# INITIATE CHANGE.

THE CHAIR'S INITIATIVES OF THE DEPARTMENT OF PEDIATRICS

**The Children's Hospital** *of* Philadelphia<sup>®</sup> Hope lives here.



# The Chair's Initiatives

In 2004, the Department of Pediatrics at The Children's Hospital of Philadelphia began a program called the Chair's Initiatives. The goal: to establish new models of care in pediatrics and tackle some of the most daunting challenges in healthcare today.

Alan R. Cohen, M.D., physician-in-chief and Department chair, and Alison Marx, Department operating officer, sought innovative proposals. They selected 10 from a pool of 65.

In the four years since, physicians, nurses and administrators leading the projects have helped so many, among them children with heart defects, young cancer survivors and families struggling with attention-deficit disorder.

They have tackled healthcare's technology challenges, creating a computer model that synthesizes data about diseases and pharmacologic drugs with patientspecific data. They have found ways to reduce the fragmentation of care for children with complex needs, creating programs to bring together specialties and coordinate care.

Each program succeeded. As funding under the Chair's Initiatives concluded in 2008, each has continued under other funding sources.

# Here Dr. Cohen shares his thoughts on their success.

**Reasons to begin:** In pediatrics today there is a lot of new thinking for which there isn't obvious funding. This was an opportunity to provide resources to people with great ideas who may have thought there was no way to move forward.

We wanted to encourage innovation and, by doing so, plan for the future of the Department and the institution. We wanted to encourage collaboration among people in different subspecialties, knowing the tremendous strengths within the Department would be enhanced by having people work together.

**Reasons for success:** The people involved in these projects were incredibly committed, enthusiastic and creative. The goal was to come up with new models of care and break down some of the old barriers. They did that.

Attention to measurable outcomes was critical. From the beginning, we pushed people to establish their goals in quantitative terms. They held themselves accountable and produced the data to reflect the success of their projects.

One of the goals here was to make sure people learned from each other. That happened because of Alison's leadership and the monthly meetings at which these very busy project leaders got together to support and encourage one another.

**For the future:** Leadership is about building the future by establishing programs that are different and will be models for our own institution and for others. Leadership is about investing in people with good ideas so they have the opportunity to try those ideas out.

With approximately \$3 million, the Department incubated 10 projects that are truly helping children and families. At the meetings, when people sat around the table and described their projects, there was a lot of ... just joy. And I think that's because all of these projects improved the care of children. You couldn't have something better to be proud about than that.

I'm committed to this program. I look forward to experiencing more successes, and joy, as we fund more innovation and encourage more change for many years to come.

This brochure includes snapshots of the comprehensive work of the first round of the Chair's Initiatives. An inventory of all activity and information on how to request copies is in the back of the brochure. For descriptions of the second round of Chair's Initiatives, please go to page 26.

# Initiate change.

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# Chair's Initiatives Access Nurse Advisor

# Goal

Partner with the Access Center's Complex Scheduling Service to improve appointment and care coordination for families seen by numerous specialties at CHOP.

# Background

CHOP patients with complex needs visit different subspecialties many times throughout the year, are commonly admitted as inpatients and access varied resources across the institution.

It is often challenging for families of these patients to keep up with scheduling demands and to communicate their needs to the various subspecialties.

With funding from the Chair's Initiatives, the Department of Pediatrics created a new position, the Access Nurse Advisor, to partner with the Complex Scheduling Service to provide clinical guidance, oversight and coordination related to scheduling, discussions with families regarding long waits for serious problems, financial counseling issues, follow-up scheduling for inpatients and resources for families at risk for not showing up to appointments due to insurance, referral and transportation issues.

# Accomplishments

- Michele Lizzi, R.N., B.S.N., was hired as Access Nurse Advisor to provide clinical oversight to ensure that patients see the right providers at the right time in the right sequence, with support for families and providers to coordinate access, communication and care.
- The Access Nurse Advisor works with the Hospital's Financial Counseling staff to ensure families are aware of insurance issues and other financial needs.
- The Access Nurse Advisor worked with the Auto Dealers CARing for Kids Foundation Welcome Center to improve the patient and family experience, including creating a welcome packet.
- A passport-like "Galaxy Guest Book" was created for patients to get "stamps" from different specialties and help identify their families as having complex needs on a particular date of service.

- The Access Nurse Advisor works with the newborn/infant intensive care unit, Integrated Care Service and other inpatient units to identify families that may need assistance with follow-up scheduling coordination before they leave the Hospital.
- As a result of needs identified by the Access Nurse Advisor initiative, in addition to Department of Pediatrics focus groups with patient families and pediatricians, a broad Care Coordination Initiative was developed and implemented and is now part of the Hospital Operating Plan. Lizzi took on a new role as care coordination counselor, and Joanne Madden, M.S.N., R.N., was hired as the new Access Nurse Advisor. (See Page 4.)
- The Access Nurse Advisor was central in creating and providing clinical supervision to a newly created Department of Pediatrics central phone line for referring physicians (See Page 4.)
- To date, the Access Nurse Advisor and Complex Scheduling have helped more than 1,770 patients and families.



# **Complex Scheduling Volume Statistics**

# **Momentum**

- Presentations: Two posters presented at 2006 and 2007 National Initiative for Children's Healthcare Quality conferences. Posters also presented at annual CHOP nursing conferences.
- Databases: Complex scheduling database created to help track trends in services provided and to support enhanced operations.
- Advisory Committee: Complex Scheduling Advisory Committee created to solicit input from and collaboration with clinicians and families on how to continue to improve service and patient experience.

# Conclusion

Families whose children have complex needs now have great help in navigating the Hospital's numerous specialties and services. The Access Nurse Advisor partners with families to make scheduling and communication less burdensome. She serves as a link among patient families, clinicians, schedulers, financial counselors, the Welcome Center and many others who come together to support families but may not always have the opportunity to easily communicate.

The findings of the Access Nurse Advisor initiative have contributed to numerous other improvements and projects. Thanks to this Chair's Initiative, and its partnerships with many across the entire institution, the systems of support for families and children for whom serious health issues are a part of daily life have been significantly improved.



# Chair's Initiatives Referring Physician Communication and

These initiatives were informed by learnings from the Access Nurse Advisor role and Complex Scheduling, in addition to Department of Pediatrics focus groups with patient families and pediatricians.

# **Referring Physician Communication**

### Goal

Improve communication, partnership and coordination between primary care physicians and subspecialties in the care of children with chronic and acute conditions.

## Background

A focus group with referring physicians was held to gather ideas for improvement. The result was several initiatives designed to enhance both communication and referring physician satisfaction.

# Accomplishments

- A central referring physician line was established to provide a central, simple mechanism for pediatricians to speak with a specialist prior to referring a patient. Staffing for the 1-877-CHOP555 line is provided by the Department of Pediatrics and supervised by the Access Center in partnership with the Access Nurse Advisor.
- Central e-mail addresses were developed for the Division of Gastroenterology, Hepatology and Nutrition and the Division of Oncology for referring physicians to ask nonurgent care management or prereferral questions of CHOP doctors.

Department of Pediatrics outpatient subspecialty letters to primary care physicians are audited annually. There has been significant improvement in completion rates and timeliness, and an increasing number are now also available on EpicCare.

> **1-877-CHOP555 Line:** Overall Referring Physician Satisfaction



# **Care Coordination**

### Goal

Support families in understanding and building core competencies in care coordination and support providers in the coordination and communication of care across multiple specialties.

# Background

Learning from the Access Nurse Advisor initiative, as well as analysis of the compelling number of patients seen by multiple subspecialties across the institution, led the Department of Pediatrics to partner with the Family Advisory Council, Nursing, Social Work and Quality and Patient Safety to conduct focus groups asking patient families the following questions: 1) What challenges do you and your family face in coordinating care across multiple specialties? 2) How can we improve communication? 3) How can we improve coordination?

The answers to these questions illustrated families' strong desires to be able to identify a "captain," "quarterback," "facilitator," "orchestrator" or "coordinator" of care for their child and to have the tools, competencies, resources and communication to play a central role in that coordination as well. These findings led to a multidisciplinary committee's development and implementation of the following initiatives.

# I Care Coordination

# Accomplishments

Care Coordination Counselor

This position serves as a resource to families and providers to:

- Facilitate communication and coordination across multiple clinical services, identifying the key "coordinator"/ point person(s) for the child's overall care plan
- Provide educational resources to support partnership and care coordination
- Develop and provide tools to support family and provider access to clinical information
- Share successful approaches, tools and resources to benefit children at CHOP, in Philadelphia and beyond

This program was staffed in 2008 and the goal is to have 200 families enrolled during fiscal year 2009.

- Family Resource Online Database was enhanced, offering families and professionals (internally and externally) the opportunity to identify resources for families with complex needs at CHOP, in the region and nationally. The new and improved intranet database was launched in the fall of 2008 and will be available to families via the Internet in 2009.
- Care Coordination Network Committee meets every other month to build, communicate and share expertise in care coordination across the CHOP network.
- Care Coordination Intranet site was launched in June 2008.



CHOP Care Binders

These binders are organizational tools for families that have children with complex health needs.

- Care binders are used to keep track of and communicate important information about a child's health and care.
- Families receive training about how to use, maintain and communicate with their care team using the Care Binder.
- Binder materials will ultimately be made available online for families (at CHOP and beyond) and providers to access.
- Binders will allow us to share successful approaches, tools and resources to benefit children at CHOP, in Philadelphia and beyond.
- The program was refined after a pilot of 100 families in the summer of 2008.

The goal is to have as many as 2,000 families use the binders in 2009.

# Chair's Initiatives ADHD in Primary Care Initiative



# Goal

Develop a better model of care for children with attention deficit hyperactivity disorder (ADHD) at the primary care level (general pediatrics).

# Background

ADHD is one of the most common behavior disorders encountered by physicians and other clinicians in primary care; it is estimated to occur in 3 to 10 percent of children. Managing ADHD requires a team: parents, school professionals, doctors and psychologists. The involvement of the primary care physician has a profound effect on the well being of the child with ADHD. However, making the initial diagnosis, deciding if medication is appropriate and monitoring its use, and communicating with families, schools and psychologists are challenges for these clinicians, who have many demands on their time.

Children's Hospital psychologist Thomas Power, Ph.D., and developmental pediatrician Nathan Blum, M.D., recognized the need for improvement. With Chair's Initiatives funding, they set out to establish a better model of care.

# Accomplishments

- Conducted surveys of primary care providers in the CHOP network to gauge their needs in ADHD care
- Examined differences in needs in urban versus suburban settings
- Evaluated the validity of a measure primary care providers commonly use to screen for ADHD and other mental health conditions
- Worked with primary care providers to develop a computer-based "SmartSet"
  - "SmartSet" puts at their fingertips information about diagnosing ADHD, options for medications, family education materials that can be printed and shared, and much more.
  - More than 100 pediatricians and nurse practitioners have been trained in the use of "SmartSet."
  - In its first 11 months, "SmartSet" was used more than 1,100 times.
- Hosted ADHD conferences in 2007 and 2008, each with more than 130 healthcare providers and parents in attendance
- Developed and tested a collaborative care model for managing ADHD and received a federal grant to evaluate its effectiveness. The program, called Partnering to Achieve School Success (PASS):
  - Helps children with ADHD residing in low-income, urban settings, who often have difficulty sustaining their engagement in treatment
  - Helps children early (elementary school)
  - Helps parents, schools, primary care doctors and community mental health systems work together to prevent school failure and parent-child conflict
  - Has a primary focus on engaging and re-engaging families in intervention



# **Feedback From Primary Care Physicians**

Primary Care Feedback (50% Response Rate)



# **Feedback From Parents**

Parent Feedback (67% Response Rate)

# Momentum

**Publications:** Two articles in peer-reviewed journals; one book chapter

Presentations: Four posters/abstracts at external conferences

**Protocols:** Three care protocols developed or tools provided to implement existing protocols

Grants: Two applied for, one received

# Conclusion

Managing ADHD is one of the most difficult and complicated challenges in pediatric healthcare today. With Chair's Initiatives support, two experts in children's mental and emotional health needs decided to take on the challenge.

As a result, pediatricians now have useful tools for diagnosing ADHD, choosing medicines and educating families. Families and children at high risk for not complying with ADHD treatment plans are participating in a program that incorporates school and family-life issues into the model of care.

These important first steps toward a more manageable, effective model for ADHD care will ultimately improve the lives of children with ADHD.

"The Chair's Initiative has enabled our team to substantially expand service delivery for families coping with attention deficit hyperactivity disorder and to develop innovative models of care for underserved families living in inner city settings."

Thomas J. Power, Ph.D.

Director, Center for Management of ADHD at CHOP

# Chair's Initiatives Automated Appointment Reminders Pro



# Goal

Reduce the frequency of missed appointments.

# Background

Missed appointments ("no-shows"), in which a patient/ family is unable to keep an appointment but does not call to cancel, are costly. The patient loses an opportunity to see a doctor, the physician and family lose continuity of care, and the practice loses the opportunity to offer the appointment to another child in need of services.

CHOP has thousands of outpatient appointments daily, in primary care and multiple subspecialties. Previously, each area placed its own reminder calls; frequency of calls depended on staffing and varied widely.

The Department of Pediatrics decided to standardize its approach and improve continuity of and access to care with an automated call system and other measures, and to determine the effect on missed appointment rates and staff and patient-family satisfaction.

# Accomplishments

### Televox Automated Call System

- Used in 115 locations across the CHOP network
- Places an average of 41,000 calls per month
- Cost is low: 15 cents per call

### Standardized Communication

- Appointment reminder letters and letters to follow up when families miss appointments
- Posters and counter cards that:
  - remind families of the importance of arriving for care
  - let them know about resources available to support them in keeping appointments
  - remind them of the importance of calling to cancel if they cannot make their appointment, so that their time can be offered to another family

### Improved Training

Schedulers and managers received training on the missed appointment policy, on the awareness campaign and on how to correctly record visit status in the computer system.

# Momentum

- Presentation/poster at National Initiative for Children's Healthcare Quality conference
- Successful transition of Televox system from IDX to EpicCare
- Televox embraced and implemented by primary care network and many surgical specialties as well
- Televox reminder calls also used to communicate about other institutional initiatives, such as EpicCare implementation, preregistration services and need for referrals
- Working with Family Advisory Council to make missed-appointment letters more family friendly and effective

# ject

# 1. 2. 3. 4. 5. 0% 20% 40% 60% 80% 100% ■ Agree ■ Strongly Agree

# Survey of Call-system Users



- 1. Our site should continue to use the Televox system.
- **2.** I am satisfied with the service provided by the Televox appointment reminder system.
- **3**. Using Televox is better than what we previously had in place in terms of reminder calls.
- **4.** Using Televox allows us to reach a higher percentage of families.
- **5.** Using Televox has freed up staff time to accomplish other essential tasks.

# Conclusion

Data from the initial phase suggests that the "no-show" rate fell by as much as 7 percent in some areas after automated calls began. However, because of the lack of consistent "before" data, arriving at a true number has been difficult.

This project has been very successful for other reasons. Patient-family satisfaction with automated calls is between 90 and 100 percent, and staff are able to allocate time toward other activities supporting patient care. Thanks to the Chair's Initiatives, a system important to patient care changed from piecemeal and inefficient to thorough and effective. Automated calls from the Department of Pediatrics' divisions are now funded by the Department's operating budget.



These posters are part of a broader public awareness campaign regarding missed appointments.

# Chair's Initiatives Center for Bone Health

# Goal

Improve care for children with bone health concerns.

# Background

Children with poor bone health are at higher risk for fracture and other injury. Chronic illness, certain medications, poor nutrition and inactivity can lead to poor bone density.

It's important to help children with chronic illness build bone mass during the crucial growing years. Evaluations of dual energy X-ray absorptiometry (DXA) bone scans and of diet, medications and activity are key; however, pediatricians and subspecialists have had difficulty interpreting scans and coordinating bone-health management for patients. Physicians from the Division of Gastroenterology, Hepatology and Nutrition recognized that changes were needed to provide comprehensive, coordinated and effective care for better bone health in children.

With Chair's Initiatives funding, they established the Center for Bone Health (CBH) at CHOP.

# **Accomplishments**

- Improved DXA process (See chart below)
- Established bone health clinic

A patient meets with a physician, dietitian and physical therapist; visits take place on one day. The team provides a bone health management plan and communicates with the referring physician. Between Jan. 2006 and June 2008, the clinic had 159 visits and continues to grow in volume of patients.

# **DXA Process**



# **Bone Health Clinic Visit Volume**



- Established monthly meeting with representatives from more than 15 subspecialties, including gastroenterology, oncology, endocrinology and pulmonology
- Established protocols for the bone health medication pamidronate
- Developed Web-based form for DXA results
- Established e-mail and phone number for easy referral to the CBH
- Number of DXAs at CHOP rose by more than 30 percent, to 750-plus annually
- Educated and trained medical students, dietitians, residents and gastroenterology fellows
- Developed program brochure, Web site and educational materials for patients and families

## Momentum

### Presentations at external conferences: Two

Feedback: In a survey of referring physicians who used the CBH, 100 percent said they would recommend it to other practices and providers.

### Conclusion

The Center for Bone Health team is helping to develop the International Society for Clinical Densitometry's clinical guidelines for the management of pediatric bone disease. The number of referrals and new patients continues to increase. The team is broadening its research: among the current goals is finding new ways to improve vitamin D status for patients unable to take oral medications.

Michael Levine, M.D., has been named the new medical director of the Center for Bone Health. He leads a team that has become a national leader in clinical care and research, and has helped many patients and families take steps toward improving bone health.

"The establishment of the Center for Bone Health under the auspices of the Chair's Initiative Program has provided us with wonderful opportunities to address collaboratively the clinical management of pediatric bone health. We have been fortunate to learn from the experiences of other Chair's Initiatives at our monthly meetings."

Maria R. Mascarenhas, M.B.B.S. Attending physician, Center for Bone Health

# Chair's Initiatives Center for Pediatric Eosinophilic Disord

# Goal

Improve care for children with the rare allergic disorder eosinophilic esophagitis and other eosinophilic disorders.

# **Background**

Eosinophilic esophagitis (EE) is an allergic reaction in the esophagus, usually caused by foods. (An eosinophil is one of the types of cells that causes the reaction.) Symptoms include nausea, vomiting, abdominal pain, a burning sensation similar to heartburn, difficulty eating and, in children, failure to gain weight.

Diagnosis is complicated, requiring numerous visits with different specialties. Treatment requires diet modification. Family support and education are also important. A team of doctors, nurses and dietitians at CHOP decided to improve the system of care for children with EE symptoms.



# **Accomplishments**

- EE clinic established so patients and families have a central source for diagnosis and care
  - Staff includes allergists, gastroenterologists, dietitians and nurses
  - Held five times per month
  - Offered at Main Campus in Philadelphia and Specialty Care Center in Exton
  - Includes extensive family education and help in modifying diet
  - To date, clinic has had more than 800 visits
- Standard treatment protocol established
- Local family support group established
- Web site, program brochure and educational materials developed
- Co-hosted national EE conference in 2006
- Advised seven other organizations, including children's hospitals, on best practices for EE care
- Staff travels the country to give lectures and raise awareness

"The Chair's Initiatives program was instrumental in providing the backbone for the development of a clinic for children with the rare allergic disorder eosinophilic esophagitis. With the help of the Chair's Initiatives program, we were able to develop new patient care guidelines and deliver optimal patient care."

Jonathan M. Spergel, M.D., Ph.D. Co-director, Center for Pediatric Eosinophilic Disorders

# ers

### **Momentum**

Publications: Nine articles published in peer-reviewed journals

Presentations: 35 presentations at external conferences

**Protocols:** Three care protocols developed or tools provided to implement existing protocols

Grants: Three applied for, one received

Philanthropic dollars: \$125,000

New care protocols: One

New databases: One

# Conclusion

EE in children is often misdiagnosed and children can go for years without help. The establishment of this multidisciplinary clinic has resulted in a more convenient way for patients to receive care, has enhanced communication and collaboration between families and clinicians, and has provided a greater opportunity to deliver effective patient education and treatment plans.

Children from all over the United States have come to the Center for Pediatric Eosinophilic Disorders at CHOP for diagnosis and treatment. In a patient satisfaction survey, more than 90 percent rated quality of care as good or excellent.

Because of the Chair's Initiatives, awareness of EE and care for patients affected by it have been greatly improved.





# Chair's Initiatives Database Development



# Goal

Develop databases and Web-based applications to meet the diverse information needs of the Chair's Initiative projects.

# **Background**

The Chair's Initiatives include numerous ambitious and unique projects. The doctors, nurses and researchers who led the projects needed help collecting, organizing and managing large amounts of information.

Recognizing the need for improved computer databases to help maximize the chances of success of each project, leaders of the Chair's Initiatives appointed a team that included physicians and programmers, and hired a new programmer to provide support.

The team, called the Physicians' Information & Networking Group (PING), sat with project leaders at the beginning, and as the projects progressed, to assess their needs.

# Accomplishments

- Heart Health Screening: Developed a database for collection, storage and analysis of data gathered as part of the Sudden Cardiac Death Prevention Program, including demographic, physical exam, echocardiography, electrocardiogram, and family history information for all enrolled patients.
- Youth Heart Watch: A new Web-based application and database was created for tracking of AEDs distributed to schools, as well as reporting of sudden cardiac death episodes in participating schools.
- Cancer Survivorship Multidisciplinary Clinic: Developed a database to allow the clinic to collect outcomes data on survivors of pediatric cancer, including information about physical exam, disease management, imaging, and laboratory measures across five subspecialties, including cardiology, endocrinology and oncology.
- Bone Health Clinic: Developed a secure, Web-based interface for technicians, clinicians, and administrative support staff, with the primary goal of streamlining workflow and enhancing data capture for the bone densitometry (DXA) test.
  - More than 3,600 historical DXA reports were back-loaded into the system, and more than 300 new DXA reports have been added.

# Conclusion

Computer databases are an important part of healthcare today because they allow physicians and other clinicians to function more efficiently. However, not all physicians know how to create databases, or have the time to do so.

The Physicians' Information & Networking Group provided much-needed support to the leaders of the Chair's Initiatives in the creation of computer databases.



# Chair's Initiatives Multidisciplinary Cancer Survivorship P

# Goal

Improve the care of the growing population of survivors of childhood cancer with multiple chronic medical conditions by developing a specialized clinic that crosses disciplines and provides access to oncology, endocrine, pulmonary and cardiology expertise, as well as nutrition and psychosocial counseling.

# Background

Children who survive cancer may experience physical or emotional problems as a result of chemotherapy, radiation or other treatments used to cure their disease. While many survivors are doing well, some have complex, long-term problems that require careful monitoring by more than one specialist. Proper follow-up requires the coordination of outpatient visits with one or more subspecialists and additional trips to the hospital, resulting in lost days from work or school. Coordinating follow-up care is difficult for these patients and parents. In addition, families often feel that the specialists involved in their child's care are not communicating with one another effectively.

Regardless of parental expertise in navigating the healthcare system, we fell short of providing an ideal patient experience for these patients. The Survivorship team within the Division of Oncology recognized the need to coordinate follow-up care for this special group of survivors. With Chair's Initiatives funding, they established the Multidisciplinary Cancer Survivorship Clinic.

# Accomplishments

### Multidisciplinary Cancer Survivorship Clinic

- Clinic is held once a month.
- Medical chart is reviewed for cancer history and treatment exposures.
- Clinic nurse coordinator organizes all appointments and risk-based screening tests so families don't have to.
- Patient is mailed a personalized schedule.

- In one day, in the same clinic location, patients see clinicians from oncology, endocrinology, cardiology, pulmonology, psychology and nutrition.
- Multidisciplinary team meets before and after each clinic day to review the patient's history, identify current problems and develop a care plan.
- Comprehensive summary letter blending visit notes from all subspecialists is created and shared with primary care physician, subspecialists and patient/family.
- Through this clinic to date, we have seen 164 survivors and these survivors have had 904 subspecialty visits.

# Momentum

Publications: Four articles in peer-reviewed journals

**Presentations:** Six abstracts/posters and three oral presentations at external conferences

Grants: Two applied for, both received

Philanthropic dollars: Attracted \$75,000 in donations

**Collaborative Research:** Several multidisciplinary research studies in progress

Model of Care: Consults with other institutions interested in developing a similar program

"The Chair's Initiatives provided us with the resources to create an innovative clinical environment for cancer survivors that improves patient care and fuels multidisciplinary research projects on the late effects of therapy. The Chair's Initiatives also provides an excellent framework for collaboration across disciplines with colleagues who share the Hospital's vision of providing the ideal patient experience."

Jill Ginsberg, M.D. Director, Multidisciplinary Cancer Survivorship Clinic

# rogram

# **Everyone Benefits!**

### PATIENT/FAMILY

- Improved access to multiple subspecialists
- Centrally coordinated care
- Less time lost from school and work
- Improved communication between oncology team and subspecialists

### **HEALTHCARE TEAM**

- Opportunity for collaborative clinical care
- Seamless provider communication and continuity of care
- Enhanced efficiency and clinical effectiveness
- Rich environment for collaborative research
- Environment to train healthcare providers regarding long-term effects of cancer therapy

### INSTITUTION

- Expansion of service line
- Increased patient volume/new referrals
- Improved patient satisfaction

# **Patient Satisfaction**

Satisfaction surveys were sent out after each clinic to give patients and families the chance to tell us their thoughts about the clinic.

- 100 percent of patients felt that their treatment plans were now more coordinated across specialties.
- 79 percent indicated that new issues about their child's health were identified during the clinic visit.
- 100 percent would use the clinic again next year.
- Through centralized scheduling of all patient visits, the clinic provided a 75 percent reduction in the number of families who had to make three or more phone calls to coordinate medical visits for their child.

### Comments from patients and families:

"I thought the whole day was wonderful and very productive."

"It was very convenient and I was able to make only one trip down to Philadelphia instead of two. (Almost two hours each way. Also missing only one day from school). I feel the new clinic is a great idea!"

"Thank you so much for coordinating everything so well. In the past, I had to miss workdays, and as a teacher it is always difficult to plan for an absence. But this one visit is great. Thanks to everyone in the clinic!"



# Conclusion

Patients and staff benefit from this novel, efficient and comprehensive clinic that attends to the complicated medical and psychological needs of survivors of pediatric cancer. Because of the Chair's Initiatives, a model of care is in place that significantly improves the service we provide to young cancer survivors who, like all children, deserve the best from their healthcare providers.

# Chair's Initiatives Office of Fellowship Programs

# Goal

Strengthen the fellowship programs at The Children's Hospital of Philadelphia, with a focus on recruiting and training physician leaders in pediatric subspecialties, developing strategies to enhance learning and teaching, and anticipating and helping to meet subspecialty workforce needs.

# **Background**

CHOP has more than 40 fellowship programs in the subspecialties under the Departments of Pediatrics, Surgery, Anesthesiology, Pathology, Radiology and Psychiatry. Each program is directed by a doctor in the subspecialty.

The programs are vital to CHOP as an institution and to pediatric medicine as a whole; in them, the next generation of specialists is trained.

The Department of Pediatrics decided that it needed a central office focused on its fellowship programs. Among other goals, the office would help each area meet accreditation criteria, eliminate inefficiencies, improve communication among subspecialties, and compile and evaluate data.

Gail Slap, M.D., M.S., formerly a CHOP fellow and adolescent medicine chief, was hired to lead the initiative, and the Office of Fellowship Programs was established.

# Accomplishments

- A Compendium of Core Curricular Resources was developed to help fellows and program directors navigate educational opportunities in the department, institution, school and university. A competency-based grid was designed to promote alignment of the educational plan with core competency requirements.
- Standard templates and processes were established to ensure that the academic development of every fellow is monitored by a scholarship oversight committee that functions according to accreditation requirements.
- The application process was standardized across all fellowship programs in the Department of Pediatrics.
- A database of CHOP fellows entering subspecialty training in or after 1993 was developed. Preliminary analyses examined post-fellowship location, position and academic affiliation, among other factors.
- A database was designed to identify factors associated with training outcomes at the individual and programmatic levels. Data pertaining to more than 400 fellows from the past 15 years was collected and analyzed.
- The CHOP Fellows' Association was reorganized. Seminars and social events are now held to promote communication across subspecialties.
- A New Fellows' Orientation was held, the first CHOP orientation designed for fellows only.
- Fellowship sites were established on both the Internet and the CHOP intranet.
- An electronic fellow-evaluation system, coordinated centrally, was selected and most pediatric programs transitioned to it.
- The Accreditation Council for Graduate Medical Education (ACGME) visited 14 fellowship programs in the Department of Pediatrics in 2007. The Office of Fellowship Programs helped each program prepare for the visits, and all 14 were accredited for the maximum allowable period of five years.
- In response to the ACGME reaccreditation letters, the Office of Fellowship Programs developed a common set of corrective actions for citations and a template for preparing action plans. Within three months, the 14 programs had action plans in place.

# Momentum

The next steps for the Office of Fellowship Programs include:

- Create a graduate medical education dashboard to track performance against goals
- Focus on innovation to improve learning and care
- Improve measurement of patient and learner outcomes
- Increase participation of fellows in patient safety quality improvement projects

# Conclusion

Because of the Chair's Initiatives, The Children's Hospital of Philadelphia's fellowship training programs, considered among the best in the nation, have become even better.

Directors spend less time on paperwork and more on mentoring. Accreditation requirements are met with less duplication of work. More is known about fellows' past and future paths, information helpful in analyzing the effects of training. Social events bring together fellows in different subspecialties, which can lead to professional collaboration.

Ultimately, all of these support CHOP's mission of improving healthcare for children.

# **Location After Fellowship**



# **CHOP Faculty with CHOP Training**



# Academic Positions Post Fellowship by Program



# Chair's Initiatives Pediatric Knowledgebase

# Goal

Create a Web-based application that combines data about lifesaving drugs with data about individual patients to help doctors make decisions in prescribing drugs and to improve pharmacotherapeutic outcomes in pediatrics. This application will improve patient safety, reduce medication errors and advance the quality of patient care at CHOP.

# **Background**

Prescribing drugs to sick children is an incredibly complicated task. There are few pharmacological studies in pediatrics, and doctors can't assume that drugs tested in adults are safe or will have the same effects in children. In addition, each patient has a unique set of characteristics. Does she have allergies? Is she taking other medications? What is the severity of illness?

A team of CHOP researchers, physicians, nurses, statisticians and pharmacists decided to build a computer system capable of mining data from individual patients' medical charts and combining it with information about certain drugs. The system, called the Pediatric Knowledgebase (PKB), will predict outcomes and help clinicians make decisions about which drugs to prescribe and in what doses.

# Accomplishments

- Developed "dashboard" for methotrexate, a chemotherapy drug
  - The team manually extracted information from patients' charts to create a computerized predictor of the effects of this drug.
  - The dashboard (a series of computerized charts) synthesizes information about each patient to help doctors and nurses monitor and manage the drug's effects.
  - The dashboard helps them decide when to use

leucovorin, a drug that inhibits methotrexate's toxic effect on cells.

- Developed dashboard for tacrolimus, a drug that reduces the risk of rejection after organ or bone marrow transplantation
  - The dashboard helps clinicians keep the drug at the optimum level. When its concentration is too high, the drug has toxic effects; too low, and organ rejection may occur.
- Developed oncology therapy dashboard
  - This more comprehensive tool will permit a broader view of the complex poly-pharmacy that exists when managing children with cancer on various chemotherapy regimens on top of the myriad of other agents they must take to manage other complications.
- Developed questionnaire to assess CHOP dosing practices and completed survey for baseline PKB assessment
  - A total of 315 physicians, nurses and pharmacists responded.
  - Approximately 80 percent considered dosing adjustments to be extremely important in pediatric pharmacotherapy.

• Approximately 75 percent said they would like to have a predictive tool to allow them to individualize treatment.

- Developed a marketing/fundraising strategy
  - Made numerous international presentations
  - Appointed external advisory board
  - Organized a successful community fundraising event

# Momentum

Publications: Two articles in peer-reviewed journals Presentations: Eight presentations at external conferences Grants: Three applied for; two pending, one denied Philanthropic dollars: \$5,000

# **Methotrexate Dashboard**



# Methotrexate Dashboard with Rescue Guidance



# Conclusion

There is a vast amount of data available in healthcare today: about diseases, about pharmacological drugs, about each patient. One of the largest challenges we face is finding ways to synthesize this data, and to use it effectively to improve patient health.

Because of the Chair's Initiatives, a CHOP team is taking crucial steps toward improving the effectiveness of pharmacological drugs in pediatrics, and creating a model for the effective use of data and technology in patient care.

# **Tacrolimus Dashboard**



# **Oncology Therapy Dashboard**

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# Chair's Initiatives Sudden Cardiac Death Prevention Program





Youth Heart Watch at The Children's Hospital of Philadelphia An affiliate of Project ADAM®

# Goal

Prevent sudden cardiac death in children and adolescents.

# **Background**

Sudden cardiac death occurs when the heart suddenly stops beating. Adults are affected most often, but children are also victims. Causes include defects in the heart or its electrical system, a blow to the chest (such as from a baseball), and drug use.

Estimates of pediatric sudden cardiac deaths in the United States range from 1,000 to 7,000 per year. There isn't a tracking system, and in many cases autopsies are not performed or are inconclusive.

Much of the public is unaware of pediatric sudden cardiac death, and many in the medical establishment think preventive efforts would be ineffective and too costly.

Victoria L. Vetter, M.D., a CHOP cardiologist for more than 30 years, is investigating changes she believes would prevent many tragedies and would be worth the cost.

# Accomplishments

### **Heart Health Screening Study**

The U.S. lacks standardized screening for heart defects; only high school athletes are screened, through physical exams and questionnaires. Dr. Vetter and her team are researching whether universal screening (testing all children) with electrocardiography is feasible.

Screened 1,100 children with electrocardiography. The chart below shows the findings.

3% with mild to moderate abnormalities



Seeking National Institutes of Health (NIH) funding for a multisite study with as many as 50,000 children

### Youth Heart Watch Program

Dr. Vetter is also an advocate of automated external defibrillators (AEDs) in schools. AEDs can restore the heart's rhythm and, in some cases, save the victim.

- Created a program to help schools obtain AEDs and CPR/ AED training
- Hired a full-time coordinator
- Provided services to 224 schools
- Distributed training grants to 39 schools; 400 staff and students trained
- Produced educational video about sudden cardiac death and AEDs

### **Youth Heart Watch Clinic**

Created care clinic for relatives of young victims of sudden cardiac death. If the cause is genetic, the family must be evaluated; medicine or other measures can prevent the tragedy from occurring in other children.

### Momentum

- **Publications:** Three articles in peer-reviewed journals
- Presentations: Four conference presentations
- Grants: Two \$30,000 grants from AED-manufacturer Medtronic
- Fundraising: Attracted \$40,000 in donations Hosted inaugural "Holes for Hearts" golf outing

# Conclusion

With Chair's Initiatives funding, Dr. Vetter and her team took significant steps toward their goals. Media coverage, fundraising and communication with schools raised community awareness of pediatric sudden cardiac death and AEDs. A resubmitted NIH grant is being modified and Dr. Vetter is hopeful that a large screening study will be funded. And Youth Heart Watch continues, funded by the Department of Pediatrics.



# The Chair's Initiatives Participants

**INITIATIVE:** ACCESS NURSE ADVISOR **Awardees:** Alison Marx, M.B.A., Mark Rodi, M.H.A. **Division:** Department of Pediatrics, in collaboration with PARC

### Team Members:

Michele Lizzi, R.N., B.S.N. Maryann Chilkatowsky, M.B.A. Joanne Madden, R.N., M.S.N. Macqueda Madison-Gaffney, A.A. Toni McCall, A.S.

**INITIATIVE:** ESTABLISHING COMPREHENSIVE AND INTEGRATED ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD) SERVICES AT CHOP **Awardees:** Nathan Blum, M.D., Thomas Power, Ph.D. **Division:** Child Development, in collaboration with Primary Care

Team Members: Jennifer Mautone, Ph.D. Heather Jones, Ph.D. Trude Haecker, M.D. Cheryl Hausman, M.D. Maggie Swietlik, M.S.N. Eli Lourie, M.D. Tony Luberti, M.D. Tony Luberti, M.D. Leslee Frye, M.S. Niccole McGowens, Psy.D. The primary care providers at the Primary Care Center at University City

### **INITIATIVE: AUTOMATED APPOINTMENT REMINDERS**

**Awardees:** Alison Marx, M.B.A., Administrative and Nurse Manager Group, CHOP IT, PARC and Marketing **Division:** Department of Pediatrics, in collaboration with the above groups

Team Members: Larry Barnes, M.B.A. Eileen Drames, M.B.A. Donald Hicks, M.B.A Marie Kelly, R.N. Administrative and nurse representation from Pediatrics, PARC, IT and Marketing

### **INITIATIVE:** BONE HEALTH CENTER **Awardees:** Maria Mascarenhas, M.D., David A. Piccoli, M.D., Virginia Stallings, M.D. **Division:** Gastroenterology, Hepatology and Nutrition, in collaboration with other specialties

Team Members: Hillary Burdette, M.D. Meena Thayu, M.D. Diane Barsky, M.D. Maria D. Hanna, M.S., R.D., L.D.N. Michael Dilenno, P.T., D.P.T., C.S.C.S.

Initiative: CENTER FOR PEDIATRIC EOSINOPHILIC DISORDERS Awardees: Jonathan Spergel, M.D., in collaboration with Chris Liacouras, M.D. Division: Allergy, in collaboration with Gastroenterology, Hepatology and Nutrition

### Team Members:

Michele Shuker, M.S., R.D, C.S.P., L.D.N. Janet Beausoleil, M.D. Chris Liacouras, M.D. Ritu Verma, M.D. Meg Meyers Tracy Floyd, R.N. Nurses and staff of the Divisions of Allergy and Immunology and Gastroenterology, Hepatology and Nutrition

### **INITIATIVE: DATABASE DEVELOPMENT**

**Awardees:** Jung Park, B.S., Bimal Desai, M.D. **Division:** Department of Pediatrics/PING, in collaboration with CHOP IT and CHOP Decision Support

Team Members: Lisa Guglielmi, Psy.D., M.S.C.I.S. John Fierraro **INITIATIVE:** MULTIDISCIPLINARY CANCER SURVIVORSHIP PROGRAM **Awardees:** Jill Ginsberg, M.D., Claire Carlson, R.N., B.S.N. **Division:** Oncology, in collaboration with other specialties

### **Team Members:**

Wendy Hobbie, M.S.N., C.R.N.P. Maureen Reilly, R.N., B.S.N. Thomas Moshang, M.D. Denise Gruccio, M.S.N., C.R.N.P. Craig Alter, M.D. Elizabeth Goldmuntz, M.D. Samuel Goldfarb, M.D. Beth Kaufman, M.D. Nancy Sacks, M.S., R.D. Mary Rourke, Ph.D. Melinda Lenhart, R.N. Daniel Weiner, M.D.

### **INITIATIVE:** OFFICE OF FELLOWSHIP PROGRAMS

**Awardee:** Catherine S. Manno, M.D., Gail Slap, M.D. **Division:** Department of Pediatrics, in collaboration with Medical Staff Affairs

**Team Members:** Gail Slap, M.D. Judy Ferraro Monica Williams

**INITIATIVE:** PEDIATRIC DRUG KNOWLEDGEBASE **Awardees:** Jeffrey Barrett, Ph.D., F.C.P., Peter Adamson, M.D. **Division:** Clinical Pharmacology

### Team Members: Mahesh Narayan, M.B., M.S.E. Sundararajan Vijayakumar, Ph.D.

Kalpana Vijayakumar, M.S. Jeffrey Skolnik, M.D. Athena Zuppa, M.D., M.S.C.E. Bhuvana Jayaraman, B.S. Dimple Patel, M.S. Erin Cummings, M.S. Olivera Marsenic, M.D. Robin Norris, M.D., M.P.H. Craig Comisar, Ph.D. Doug Marsteller, Ph.D. Jason Williams, Ph.D.

### INITIATIVE: SUDDEN CARDIAC DEATH PREVENTION PROGRAM Awardee: Victoria L. Vetter, M.D. Division: Cardiology

Team Members: Danielle Main, B.S. Noreen P. Dugan, R.N., B.S.N., HP(ASCP)

# Chair's Initiatives Monthly Committee Membership (in addition to initiative representation):

Alison Marx, M.B.A., Pediatrics Maryann Chilkatowsky, M.B.A., Pediatrics Sara Barton Johanna Beliveau, R.N., B.S.N. April Taylor, M.H.A. Rachel Hezlep Zan Hale, B.A. Mark Queirolo Lara Khouri, M.B.A., M.P.H.

### Chair's Initiatives Review/Selection Committee:

Alan R. Cohen, M.D. Catherine S. Manno, M.D. Donald F. Schwarz, M.D., M.P.H. Garrett Brodeur, M.D. David Piccoli, M.D. Stephen Ludwig, M.D. Steven Douglas, M.D. Bernard Kaplan, M.D. Elaine Gallagher, M.B.A. Michael Corbo, C.P.A. Alison Marx, M.B.A.

# The Chair's Initiatives Momentum

After the success of the first round of Chair's Initiatives, the Department of Pediatrics sought more proposals and embarked on another round of innovative projects.

Quality and Patient Safety is the theme of the second round. Awardees were identified from a group of outstanding and thoughtful proposals and reviewed by a multidisciplinary departmental committee.

Funding begins Jan. 1, 2009. Representatives from each program will meet monthly to monitor progress, exchange ideas, identify areas for collaboration, review performance metrics, learn from each other's experiences and meet with departmental and institutional resources.

# The New Chair's Initiatives

### Anticoagulant Management Program

Leslie Raffini, M.D., Robert Mullen, Pharm.D.

**Goal:** To develop and implement guidelines that will improve the effective use of anticoagulant therapy, as well as reduce the likelihood of patient harm associated with anticoagulation. This multidisciplinary, Hospital-wide initiative will include computerized clinical decision support, extensive provider and patient education, and pharmacy oversight.

### Chemotherapy Tracking System

Charles Bailey, M.D., Ph.D., Christopher Forrest, M.D., Ph.D.

**Goal:** To develop a chemotherapy tracking system that is able to use both information directly provided by clinicians (for example, treatment plan) and data from Hospitalwide operational systems (for example, medication administration) to create an integrated and accurate view of a patient's treatment history.

### From Knowledge to Practice: Developing the Infrastructure to Create and Implement Collaborative Clinical Pathways

Susan Coffin, M.D., M.P.H., Jane Lavelle, M.D., Cynthia Jacobstein, M.D., Lina Matta, Ron Keren, M.D., M.P.H., Mark Magnusson, M.D., Theo Zaoutis, M.D., M.S.C.E.

**Goal:** To develop the infrastructure required to support the ongoing development, implementation and evaluation of expert consensus and evidence-based practices for common and uncommon clinical conditions in patients whose care crosses multiple clinical settings and is provided by multiple clinical groups. This initiative will begin with the development, monitoring and evaluation of a pathway for neonatal fever.

### Department of Pediatrics CHOPLink Implementation, Quality and Safety Team

David A. Piccoli, M.D.

**Goal:** To develop a multidisciplinary clinical team with significant IS expertise and commitment to quality and patient safety that will assist in the design and implementation of CHOPLink (with a focus on Ambulatory) for the Department of Pediatrics and the institution.

### Intestinal Rehabilitation Program

Rose Graham-Maar, M.D., Mike Posencheg, M.D., Allison Ballantine, M.D., Joy Collins, M.D., Brenda Waber, R.D., C.S.P., C.N.S.D., L.D.N., Maria Mascarenhas, M.B.B.S.

**Goal:** To provide inpatient and outpatient care for patients with short bowel syndrome. This initiative will foster close collaboration across Gastroenterology, Hepatology and Nutrition; Neonatology; General Pediatrics; General Surgery; and Clinical Nutrition in order to unify care and improve patient safety and outcomes.

### Unit-Based Patient Safety Walk-rounds and Quality Improvement Committees

Kathy Shaw, M.D., Anne Reilly, M.D., Allison Ballantine, M.D., Lisa Zaoutis, M.D., Jackie Evans, M.D., Paul Aronson, M.D., Beth Esposito-Herr, R.N., Ph.D., Annette Bollig

**Goal:** To create, test and implement a unit-based model for advancing the culture of patient safety. This system will include a system of unit-based walk-rounds linked with a quality and patient safety forum or Continuous Quality Improvement Committee. Walk-rounds will act as a means of identifying important patient safety issues. The unitbased quality and patient safety or CQI Committee will be a forum for advancing nurse/physician partnership, reviewing performance data and safety events, identifying the highest priority for improvement, and ensuring that actions are taken to improve the needed processes.

# In Praise of the Chair's Initiatives Program

"The Chair's Initiatives program has offered us the opportunity to think out of the box, to develop a program that advances the mission across divisional lines. The Initiatives support imagination and innovation, two key drivers that can change the way we practice pediatrics."

Michael Levine, M.D. Director, Center for Bone Health

"The Chair's Initiatives has provided an important bridge between innovative research and the patients that walk through our door every day. Projects like the Pediatric Knowledgebase (PKB) have connected clinical pharmacologists, pharmacometricians, and informatics scientists with caregivers, and have the potential to deliver on the promise of personalized medicine by providing patient-specific drug therapy guidance to improve patient outcomes. The PKB, through the generous support of the Chair's Initiative, has the potential to improve both the quality and cost of healthcare."

Mahesh Narayan, M.B., M.S.E. Project manager, Pediatric Knowledgebase

"The monthly Chair's Initiatives meetings were an inspiration and a time of professional sharing that I have never experienced in my career before. Being part of this program has truly been a wonderful experience!"

Michele Lizzi, R.N., BSN Care Coordination Counselor "The initiative to reduce missed appointments and support continuity of care for our patients greatly benefited from a collaboration among clinicians, administrators, Public Relations, PARC, IT/ CHOPLink and the Family Advisory Council. The Chair's Initiatives meetings provided a wonderful arena for feedback regarding automated appointment reminders, our public relations campaign and other aspects of the initiative. It was truly an effort that crossed departments and disciplines to benefit patients and their families as well as providers of care."

**Alison Marx, M.B.A.** *Operating officer, Department of Pediatrics* 

"The Chair's Initiative launched an educational strategy that was new for the department and institution. The development of the Office of Fellowship Programs reflected both the successes of subspecialty training in the department and the challenges accompanying those successes. I hope the Office provides a home for fellows and program directors that promotes educational efficiency and best practices across divisions. Measures of its success may be its work with other CHOP departments and dissemination of its model to other institutions."

Gail Slap, M.D. Director, Office of Fellowship Programs

"We have benefited from interacting with the other Chair's Initiatives groups by being able to share our accomplishments and hear about theirs."

Victoria Vetter, M.D. Medical director, Youth Heart Watch

# Access Nurse Advisor

A Department of Pediatrics Chair's Initiative

### Project Goal

Implement Nurse Advisor position to work with the Patient Access and Revenue Cycle (PARC) Access Center to provide clinical guidance, oversight, and coordination related to:

Complex scheduling
 Discussions with families with potential long waits for serious problems

(R)

- Financial counseling issues
- \* Follow-up scheduling for inpatients
- Resource for families at risk for no-showing due to insurance, referral, and

transportation issues.
Implementation and Clinical Supervision of a Referring Physician Phone Line (1-877-CHOP-555)

# Implementation/Accomplishments

Nurse Advisor reviews requests, ensures appropriate sequencing based on the clinical findings for the child.

Developed system and resources to improve experience of patients and families who do not meet criteria.

Developed Partnership with Financial Counseling and Family Health Coverage to ensure issues are addressed prior to visit.

> Partnered with the Welcome Center to improve patient and family experience while here at CHOP. Welcome Center is providing "Welcome Packet" which

includes the Family Satisfaction survey and the Galaxy Guestbook.

> Enhanced communication with Divisions through ongoing networking and response to customer satisfaction.

Focus Group held in February 2007 to assess satisfaction with service and learn about opportunities for improvement which resulted in 2 efforts:

 $\checkmark$  Improved timeliness of Itineraries to families and physicians

Improved communication regarding status of referral

Ongoing partnership with Physician Referral Service to increase CSR's out-ofnetwork referrals.

Referral form to enhance communication between provider and Access Nurse and Complex Scheduling Resource available through the EMR (Epic).

Approval and hiring of Care Coordination Counselor to provide additional supports to patients and families receiving multiple services at CHOP and other organizations.

> NICHQ Poster Presentation in March 2007 to share best practices.

### Volume Statistics

#### **Referral Sources**

Pre-Nurse Advisor: 6 Medical Specialties

Post-Nurse Advisor: 17 Medical Specialties, 6 Surgical Specialties, Inpatient Services, 4 PCC and multiple KF Practices

> Manual tracking system:



New! Access Database for Tracking:



### Process Measure

GALAXY

GNEST BOOK

00

#### Turn Around time: Referral to Completed Itinerary



### 1-877-CHOP-555

Hired and oriented a new staff member to pilot the Referring Physician Phone Line with one Primary Care Center and one Kid's First Practice (December 2006); rolled-out across network in summer 2007and beyond the CHOP network in fall/winter 2007/2008; also added mechanism for General Pediatrics direct admissions.

Overall Satisfaction (n=32)



Call Volume



### Next Steps

Ongoing evaluation of outcome and performance measures: Satisfaction Survey Results (ongoing survey process for Families, Divisions and Referring Physicians)

 $\ensuremath{\diamond}$  Volume statistics, including In and Out-of-Network Referrals

Turn around time from initial referral to completed itinerary Other Project Initiatives and program enhancements:

Further development of electronic databases for the Complex

Scheduling and 1-877 line to maximize functionality and report writing Complete Process Flow and conduct gap analysis to identify additional areas of opportunity for improvement

# Establishing Comprehensive and Integrated ADHD Services

A Department of Pediatrics Chair's Initiative

### **Project Goal**

To develop a model demonstration project of integrated and comprehensive services for children with ADHD in CHOP's primary care sites that identifies services needed to more efficiently assess and treat ADHD across Primary Care and Kids First sites.

Collaborate with primary care physicians in two Primary Care sites and two Kids First Practices to implement an assessment and treatment model that utilizes the resources of the ADHD Center to allow for more efficient and effective treatment of ADHD across the sites.

Evaluate the quality of care and cost-effectiveness of a model of ADHD care that integrates service delivery across primary care and tertiary care sites.

### **Care Delivery**



# Implementation / Accomplishments

#### Year 1 Accomplishments:

- Needs Assessment: surveyed providers in CHOP's primary care network to examine their roles and challenges related to the management of ADHD.
- Presented the findings of the survey research at the annual meetings of the Society for Developmental and Behavioral Pediatrics.
- Collaborated with primary care providers to develop electronic templates to guide the initial assessment and ongoing follow-up of children with ADHD.
- Initiated the development of a psychosocial intervention that can be provided to families of children with ADHD served through urban-based primary care practices.
- Initiated a program to train primary care providers to provide brief behavioral treatment to families of children with ADHD.

#### Year 2 Accomplishments:

Needs Assessment: conducted a study examining primary care providers' perceptions of their role and the feasibility of managing ADHD in primary care, and evaluated differences between providers in urban versus suburban settings. A paper describing this study has been published in the January 2008 *Pediatrics electronic pages*.

Trained over 100 pediatricians and nurse practitioners across CHOP's primary care practices in the use of the EPIC Smart Set to promote evidence-based practice and standardize the management of ADHD.

Developed a unique psychosocial intervention, known as Partnering to Achieve School Success (PASS), for the families of children with ADHD residing in lowincome, urban settings, who often have difficulty sustaining their engagement in treatment. A chapter describing this program will appear in the Handbook of Prevention Science.

> Maternal Child Health Bureau awarded grant to evaluate the PASS program.

Evaluated the validity of a commonly used measure to screen for behavioral health problems in primary care settings. A paper describing this study will soon be published in the *Journal of Developmental and Behavioral Pediatrics*.

Participated in a pilot study of the acceptability of using a nurse case manager to facilitate ADHD care in an urban primary care practice.

In partnership with the Connelly Center, developed appropriate Parent Education material that is now available through the Smart Set and Parent Education Handbook.

#### Conference: Managing ADHD Across the Lifespan

> Planned and hosted this multidisciplinary conference in October 2007

Over 225 participants including Primary Care Providers, Sub-specialists, and Mental Health Providers.

> Greater than 50% of people in attendance were parents of children with ADHD.

### Epic Smart Set

- Designed to standardize care for the assessment and management of children with ADHD in CHOP's Primary Care and Kids First practices:
  - Reduces barriers and increases the willingness of physicians to take on role of managing children with mild to moderate disorders within the primary care setting.
    - ✓ Improves ADHD services through primary care
    - Improves medication management
  - ✓ Improves overall functioning for these children with ADHD
- > 90 Pediatricians trained in the use of the Smart Set
- Links imbedded for Parent Education materials
- > Over 50 options for prescribing appropriate medications
- > Working with Epic team to extract data for assessing utilization

### Satisfaction Measures

Partnering to Achieve School Success (PASS) Satisfaction Measures

Primary Care Physician (50% Response Rate)







# **Open Issues / Challenges**

Maintaining the ADHD Smart Set as new treatments and information becomes available

- Evaluating the efficacy of PASS
- > Supporting PCPs as they become more involved in ADHD and other behavioral health issues (e.g. autism, depression, obesity)

# **Next Steps**

- Conduct evaluation of PASS with funding from the federal Maternal Child Health Bureau
- Coordinate CHOP team to improve behavioral health services in primary care

 Improve measures for screening behavioral health and academic problems in primary care

# Automated Appointment Reminders & **No-Show Reduction Initiative**

# A Department of Pediatrics Chair's Initiative

## Project Goal

\* Pilot, in designated outpatient specialties, an automated appointment reminder system that is compatible with both IDX and EPIC

- \* Determine the impact of the automated reminders on: no-show rates,
- appointment line telephone access/answer rates and patient satisfaction. \* In a parallel fashion, implement "best practices" for reducing no-show's

across the Department, including the pilot of a No-Show Awareness campaign with Public Relations

# Implementation/Accomplishments

> Public awareness Campaign (No Show? Oh no!) developed in partnership with Public relations and there is ongoing use of the following materials/campaign:

· Additional page for Appointment Reminder letters sent to families

- The importance of keeping their appointments
- ✓ The resources available to them to help them keep their appointment (support re: insurance, directions, transportation and other issues).
- ✓ The importance of notifying the divisions at least 48 hours in advance if they do need to cancel/reschedule an appointment, and the appropriate number to call for the relevant division.

· Other materials include counter cards and messaging at the Welcome Center and appointment cards with matching images

>Training of Divisional Staff re: No-Show Initiative completed and included:

- ✓ Definitions of No-Shows vs. Cancellations and how to enter patient status How to use scheduling to ensure that statistics are correct

  - ✓ Public Awareness Campaign

✓ Department of Pediatrics No-Show Policy and Letter

> Automated Appointment Reminder System (TeleVox) rolled out to 115 locations across CHOP network including Pediatrics, Surgery, Kids First, Primary Care, and Psychology. Also partnering with CHOPlink PARC to continue roll out through EPIC



> Successful transition from IDX to Epic with the PARC Go Live

> NICHQ Poster Presentation in March 2007 to share best practice ideas and lessons learned

> Creation of IDX statistical dashboard to track and trend arrived, no-show'd, cancelled and bumped appointments; working to receive similar information in EPIC.

Transition of No-Show letters from IDX system to EPIC system





### Performance Measures



### Call Volume and Related Expense



# **Next Steps**

\* Updating of Department of Pediatrics No-Show/Missed Appointment Policy

Roll-out of "No-Show, Oh-No" posters in the Wood building

\* Ongoing meetings of committee to discuss strategies to enhance showrate Rev. 2/7/08

# A Multidisciplinary Model for Long Term **Cancer Survivor Care**

# A Department of Pediatrics Chair's Initiative (2007)

### Background

Long-term survival for children with cancer is often achieved at a considerable price in terms of medical and psychological sequelae. While many require routine follow-up and surveillance, a cohort of survivors require comprehensive management of complex, chronic medical issues by multiple subspecialists. For these patients, an requires the coordination of multiple outpatient visits with one or more subspecialists. and additional trips to the hospital, resulting in lost days from work or school. Regardless of parental expertise in navigating the health care system, hospitals often fall short of providing an ideal patient experience for these patients. As a result necessary follow-up may be sporadic or, in some cases, missed entirely. A model that provides same-day, same-clinic access to the survivorship expertise of multiple subspecialists is being piloted at CHOP.

### Challenges for Survivors with Multiple Medical Needs

- Physicians with appointments on varying days of the week
- Missed time from school and work for medical appointments
- Difficulty coordinating necessary follow-up visits/diagnostic testing
- Facilitating communication between different providers involved in care

### A New Approach: A Multidisciplinary Model of Care

Survivor One Appointment One Location

Same Day Service

Late Effects Visit Treatment History Physical Exam Risk-Based Screening

& Counseling

Anticipated Benefits Patient \*Improved access to multiple subspecialists \*Less time lost from school and work \*Improved communication between late effects team and subspecialists Healthcare Provider \*Opportunity for collaborative clinical care \*Seamless provider communication and continuity of care \*Enhanced efficiency and clinical effectiveness \*Enhanced efficiency and clinical effectiveness \*Enhanced efficiency and clinical effectiveness \*Enhanced efficiency and service line Tastitution \*Expansion of service line \*Increased patient volume/new referrals \*Improved patient (customer) satisfaction

### Care Delivery

Clinic is held once per month

- Patient visits are centrally coordinated by nurse
- Chart is abstracted for cancer history and treatment exposures
- Required risk based screening and subspecialist visits are scheduled for the survivor

Patient is mailed personalized schedule and letter which provides information for referrals

\* History and Care plan reviewed at multidisciplinary pre-clinic conference

Problem list generated at visit, interventions recommended and plan for follow-up developed

Plan of care for each patient discussed in multidisciplinary post-clinic conference \* Comprehensive summary letter which blends visit notes for all subspecialists is created and is shared with primary care physician, subspecialists and patient/family

#### **Program Measures**

<u>Clinic Utilization</u> (January 2006 through October 2007) Since January 2006, we have held 22 Multidisciplinary Clinics and have seen 144

individual natients

 Total # Specialty Encounters: 677 Total # Ancillary Encounters: 482

#### TABLE I. New Patient Visits By Subspecialty (January 2006- October 2007)

Specialty	# New Patient Visits**	Total Patients	% of Total Which Are New
SURVIVORSHIP	38	127	29%
ENDOCRINE	32	114	28%
PULMONARY	56	67	84%
CARDIOLOGY	36	56	65%
PSYCHOLOGY		93	Consider All Known To Us
NUTRITION		77	Consider All Known To Us

\*\*These are patients that were never seen prior to the Multidisciplinary Clinic by that specialty and represent new revenue for the Division.

#### Program Measures (cont.)

Table II. Patients with New Problems Identified (January 2006-October 2007)

Specialty	# Patients	# Clinics
SURVIVORSHIP	37	22
ENDOCRINE	45	22
PULMONARY	26	19
CARDIOLOGY	18	15

Table III. Past Referral Without Follow-Up (January 2006-October 2007) \*Patients referred to Specialist in past but never followed through and were captured in Multidisciplinary

Specialty	# Patients	# Clinics
ENDOCRINE	16	22
PULMONARY	5	22
CARDIOLOGY	9	15

#### Patient Satisfaction

Clini

Patient Satisfaction Surveys are sent out within a week of the clinic visit.

Surveys returned to date= 65 (45% return rate).

> 100% of patients felt that their treatment plans were now more coordinated across specialties

79% indicated that new issues about their child's health were identified during the Multidisciplinary visit

> 100% would use the clinic again next year

Through centralized scheduling of all patient visits, the clinic provided a 75% reduction in the number of families who had to make 3 or more phone calls to coordinate medical visits for their child

#### Billing & Revenue

Overall Collection Rate 45%

DIVISION	AMOUNT CHARGED	COLLECTED TO DATE	OUTSTANDING CHARGES TO BE COLLECTED
CARDIOLOGY	\$95,845	\$41,739	\$7,328
ENDOCRINOLOGY	\$48,765	\$25,937	\$2,291
ONCOLOGY	\$57,955	\$25,097	\$4,325
PULMONOLOGY	\$69,315	\$28,724	\$7,730
TOTALS	\$271,880	\$121,497	\$21,674

#### **Scholarly Activities**

Research

Several investigator initiated research protocols are taking place as a direct result of the collaborative efforts of the subspecialists involved in this clinic including:

\*\*IRB # 2005-9-4530: Ovarian reserve in female cancer survivors as compared to healthy age matched controls > \*\*IRB #: 2006-8-4926: Assessing Testicular Function in Survivors of Childhood Brain Tumors

IRB #2004-1-3600 Pulmonary Function Abnormalities in Children Who Have Received Stem Cell Transplant

\*\*IRB # 2005-5-4332: Late effects in survivors of tandem peripheral blood progenitor cell transplant for high-risk neuroblastoma as well as single transplant survivors

> IRB # 2007-4-5318: Evaluation of EKGs and Holter Monitors in Childhood Cancer Survivors at Risk

#### Abstracts

Studies marked with "\*\*" will be submitted as abstracts to the 10th International Conference on Long-Term Complications of Treatment of Children and Adolescents for

#### Cancer to be held June 6-7, 2008, Niagara-on-the-Lake, Ontario, Canada Publications

Manuscript accepted for publication in Jan 2008 Journal of Pediatric Oncology Nursing Carlson, CA, Hobbie, W, Brogna, M, & Ginsberg, JP. A multidisciplinary model of care for childhood cancer survivors with complex medical needs. Journal of Pediatric Oncology Nursing, Accepted for publication 1/08.

#### Challenges of Clinic Coordination

\* The primary challenge for the Multidisciplinary Cancer Survivorship Clinic is limited clinical space.

### **Future Funding**

\* The team has worked with hospital development to find resources to support the work of the Multidisciplinary Clinic in the future. To date, we have secured \$70,000 in funding from AFLAC and Nationwide.

#### **Conclusions and Future Plans**

The Multidisciplinary Model for Survivorship Care offers a unique opportunity to improve the care that is offered to long-term survivors with more complex medical needs. By providing same day, same clinic access to multiple subspecialists with survivorship expertise, an environment is created which supports clinical efficiency and fosters seamless patient centered care.

> Continue collaborative research

Consider expanding scope of services offered by intermittently including other sub-specialties in

clinic

Expand marketing efforts to reach patients outside CHOP catchment area > Serve as model of care for other cohorts with chronic, complex medical needs

Subspecialist(s) Visits Endocrinology Pulmonology Psychology Cardiology

Nutrition

# **Center for Bone Health**

# A Department of Pediatrics Chair's Initiative

### **Project Goal**

The Center for Bone Health was established to provide coordinated, comprehensive care to children with bone health concerns. This includes children with evidence of osteopenia, osteoporosis, multiple fractures and children who are at risk for osteopenia and osteoporosis because of such factors as chronic disease, immobility, dietary restrictions or chronic steroid use.

To become the national leader in clinical care and research related to Bone Health in concert with the NIH 2000 Osteoporosis Conference Consensus Statement that called for research strategies to identify and intervene in disorders that compromise attainment of peak bone mass in children with chronic disease (between a third and one half of all children will have at least one fracture by the end of their teenage years).

### **Care Delivery**

♦ A coordinated effort among physician, dietitian and physical therapist that provides an Interdisciplinary Care Plan to the Primary Care Physician, Bone Health Center Team, Specialists, and the patients' families



# Implementation/Accomplishments

#### **Operations**

Multidisciplinary Collaborators' meeting held monthly to provide guidance on complex clinical care, standardize protocols, develop patient education materials and inform research arm.

 Process Flow established for clinic operations including patient identification, scheduling, pre-work, registration, clinic flow, billing and obtaining co-payments
 Collaboration with Development to secure funding for the Center, and

specifically for the Program Coordinator position, physician support, and educational activities

#### **Clinical**

Developed web-based form of DXAs, implemented June 2006 which has received extremely positive feedback from users

Established protocol for IV Pamidronate in collaboration with Pharmacy and Day Medicine, first patient received treatment in August 2006

IV protocols presented to the Therapeutic Standards Committee in November 2006 for inclusion in CHOP formulary to establish consistent clinical practice for patients receiving bisphosphonates

 $\succ$  IV Pamidronate orders revised in May 2007 to accommodate patients with renal involvement

> In collaboration with Pharmacy, protocols in development for oral

bisphosphonates and vitamin D3 supplementation

In collaboration with Lung Transplant, established process for screening and patient follow-up pre and post transplant; clinic visits to begin February 2008 (~15 patients)

#### Research & Education

**Center for Bone Health** 

- > Monthly Collaborators' meeting to include clinical and research collaborations
- $\succ$  Participated in education and training of dieticians, medical students, residents, and Gastroenterology and Nutrition fellows regarding Bone Health

 Developed Patient / Family Education on DXA, Calcium and IV Pamidronate protocols

 Program Coordinator was invited and presented at the annual North American Cystic Fibrosis Conference in October 2007

Collaborators are involved in the development of clinical guidelines for the management of pediatric bone disease through the International Society for Clinical Densitometry

#### Marketing and Business Development

 $\succ$  Developed and distributed brochures across the CHOP network and identified business development strategies for in and out of network referrals

> Go Live with Internet site through the Division of GI, Hepatology, and Nutrition

### DXA Process Improvement

Prior to the establishment of the Center for Bone Health, Pediatricians and sub-specialists had little resource for the interpretation and implementation of recommendations for patients receiving DXA scans. Now, the need for consultation with CBH is suggested on the DXA report. Patients seen in CBH, are provided with detailed plan and education about their bone heath. Referring physicians receive a letter documenting a comprehensive plan for the management of their patients.



> 87.5% of Providers Agreed or Strongly Agreed that the establishment of the CBH has enhanced their comfort level for their patients with abnormal DXA Scans, that they will have a resource to partner and address their bone health needs.

#### Performance Measures

#### **Satisfaction**

Patient and Family Satisfaction and Referring Physician Survey developed Fall of 2007, implemented January 2008.

> 100% of Providers Agreed or Strongly Agreed that they would recommend the Center for Bone Health to other practices and providers.

Volume Statistics (through Dec. 2007) New! Established 2 easy ways to refer to the CBH:

Referrals: 105 New Patients: 79 Follow-up Visits: 19





#### Care Coordination:

There are 15 subspecialty divisions and 9 other disease specific programs that are also involved in the care of these children with complex needs.

### Challenges

Difficulty developing a database that will interface with the current electronic documentation systems to provide timely information regarding patient outcomes

Increasing awareness among providers regarding the identification and timely referral of patients at risk for bone disease

### Next Steps

Complete protocol for oral bisphosphonates and Vitamin D supplementation
 Implement forearm and distal femur DXAs for patients unable to complete

lumbar spine and whole body scan
 Explore ways to improve vitamin D status in patients unable to ingest oral supplements

- \* Revise web based DXA report
- Go Live with CHOP intranet site
- Planning for EPIC implementation
- Continue to identify and develop research as
- Continue to identify and develop research opportunities

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# Food Allergy Center: Eosinophilic Esophagitis Clinic

A Department of Pediatrics Chair's Initiative

## Project Goal

To establish a coordinated and multidisciplinary care approach for patients with a particular form of food allergy known as Eosinophilic Esophagitis (EE). IMPACT:

There are approximately 400 children diagnosed with EE yet only 20% are currently seen in the Food Allergy program. PROGRAM GOALS:

- Facilitated scheduling to improve patient and referring physician satisfaction Standardized treatment guidelines for children diagnosed with EE

> Develop an interdisciplinary and integrated care plan including Allergy, Gastroenterology and Nutrition. > Enhance family services through education, support groups, and website

development. Development of a patient database to track improvements and support research efforts

> Become a national leader in care of EE patients and at the forefront of clinical and basic science research.

# Implementation/Accomplishments

Joint clinic established between Allergy and Gastroenterology, expanded to 5 sessions a month (4 - Wood, 1 - Exton)

- \* Standardized Treatment Protocol developed and approved by both divisions.
- Patient Education material developed and approved, with ongoing
- enhancements based on patient / family feedback.

Participate in local Family Support group (held every other month) which includes education and therapeutic discussion.

Program brochure and Website developed and completed.

# Scholarly Activities / National Impact

CPED team members raising national and international awareness and standards through healthcare lecture circuit.

- > Hosted Family from Extreme Makeover Home Edition, National TV broadcast scheduled Dec. 7, 2007.
- > CHOP co-hosted national EE conference in August 2006, where several CPED team members presented (\$40,000 raised).
- > International Consensus meeting on EE scheduled for March 2008 in
- Philadelphia, chaired by Drs. Spergel and Liacouras.

> 6 peer-reviewed journal articles published.

> CHOP hosted 2 institutions (National Jewish Children's Hospital (Denver) and University of CA (San Diego)) to share best practice and program development strategies; phone consultation with 5 other organizations.

> Collaboration between the Food Allergy Center (EE Clinic) and The CCEB and other primary investigators using our EMR (Epic) as a case control study on risk factors; other NIH grant funding pending

# Volume Statistics

Total Patients for 2006 - 2007: 621

New Visits: 232 or 37%





# Volume Statistics (cont.)

#### New Patient Referrals:

52% of new patient visits are out of our primary referral region (n=120): 55% from PA, NJ, DE

45% from other states (18 states and Washington, DC)

\* Our reach is broadening throughout the nation and globally with one patient seen from Canada

## Patient Satisfaction

#### Satisfaction with Scheduling Process





#### **Overall Satisfaction** Information to feel PREPARED





# Philanthropic Dollars

We have successfully raised \$111,406 in funds for this program!

### Next Steps

Ongoing evaluation of performance measures:

Family Satisfaction survey

Volume and Referral statistics

Other Project Initiatives and program enhancements:

- \* Develop Referring Physician Satisfaction survey
- \* Completion of database to support operations and research

Continue philanthropic efforts for ongoing financial support

# © Office of Fellowship Programs

# A Department of Pediatrics Chair's Initiative

### **Project Goals**

- Recruit, train, and retain physician leaders in the pediatric subspecialties
   Develop innovative, efficient strategies that enhance learning and teaching across the pediatric subspecialties
- Anticipate and help meet subspecialty workforce needs within the department, institution, and field

### **Specific Aims**

- Provide an institutional home for fellows and program directors
- Establish and maintain a compendium of core curricular resources at CHOP, the School of Medicine, and University
- Improve the process and outcome of programmatic reviews
- Develop Internet and Intranet sites that convey the depth and breadth of CHOP fellowship training; provide useful information to applicants, fellows, and program directors; and improve communication across programs
- Design, pilot, and implement a centralized electronic toolkit for evaluations, learning plans, and other outcome data
- Develop a data base that tracks professional development before, during, and after fellowship training

#### 

- Staff, space, and support were allocated for the new Office of Fellowship Programs (OFP), and a virtual home on the CHOP Intranet was developed for fellows and program directors.
- The OFP established strong working relationships with key contacts in the Stokes Department of Research Education, Vice Dean's Office of Graduate Medical Education (GME), CHOP GME Committee, Accreditation Council for GME (ACGME), and American Board of Pediatrics (ABP).
- Standard templates and processes were established to assure that the academic development of every fellow is monitored by a scholarship oversight committee that functions according to ACGME and ABP requirements.
- A Compendium of Core Curricular Resources was developed to help fellows and program directors navigate educational opportunities in the department, institution, school, and university. A competency-based grid was designed to promote alignment of the educational plan with core competency requirements.
- The CHOP Fellows' Association was reorganized with OFP guidance and support. Monthly dinner seminars and quarterly social events are now held to promote communication and networking across subspecialties.
- A database of all CHOP fellows entering pediatric subspecialty training in/after 1993 was developed. Preliminary analyses were performed exploring the association of subspecialty and enrollment in a degree-granting program with post-fellowship location, position, and academic affiliation.
- The application process was standardized across all fellowship programs in the Department of Pediatrics with centralized academic review prior to submission of match lists or extension of offers.
- In 4/07, ACGME site visited 14 fellowship programs in the Department of Pediatrics. In 12/07, ACGME accredited all for the maximum allowable period of five years. In preparation for the site visits, the OFP developed template documents and program-specific appendices, conducted preparatory internal reviews, and prepared program-specific materials for presentation at site visit.

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- Year 2 opened with the New Fellows' Orientation, representing the first CHOP orientation designed and delivered for fellows only. It is a collaborative effort required of all incoming fellows that incorporates strong, consistent messages about safety, effectiveness, and patient/family rights.
- The Fellowship Internet site was launched to improve public access to information about the CHOP training environment, program-specific details, application, and selection.
- An electronic evaluation system coordinated centrally has been high priority for the OFP since its inception. The Oasis platform was selected; evaluation tools were developed and pilot-tested; and staff were trained in roll-out, adaptation, and maintenance By the close of year 2, the toolkit was complete and nearly all pediatric programs had transitioned to Oasis.
- In response to the ACGME re-accreditation letters received by programs in 12/07, the OFP developed a common set of corrective actions for citations that crossed programs and a template for preparing program-specific action plans. Within 3 months of letter receipt, the 14 programs had action plans in place.
- The fellowship data base project is designed to identify factors associated with training outcome at the individual and programmatic levels. The OFP has collected, cleaned, and analyzed data pertaining to over 400 fellows in the Department of Pediatrics over the past 15 years.





GME dashboard to track performance against goals

Focus on innovation to improve learning and care

Improved measurement of patient and learner outcomes

Increased participation of fellows in patient safety quality improvement projects

**Office of Fellowship Programs** 

# PediatricKnowledgebase

"Knowledge Heals"

# A Department of Pediatrics Chair's Initiative

### **Project Goal**

The Pediatric Knowledgebase (PKB) aims to improve pharmacotherapeutic outcomes in pediatrics. It provides a comprehensive, drug therapy-focused view of patient records combined with scenario-based forecasting of patient response to therapy. The PKB utilizes data from CHOP's EMR. A primary outcome of the PKB project is to establish a methodology by which drug-specific dosing guidance can be incorporated into hospital decision support and made accessible to care givers to help manage their individual patient's pharmacotherapy. The PKB will improve patient safety and reduce medication errors, advancing the quality of patient care at CHOP.

## Implementation/Accomplishments

We have constructed a Tacrolimus (TAC) Dashboard (DB) and an Oncology Therapy DB by manually extracting data from charts over the past year. Figure 1, illustrates a snapshot of the TAC DB, depicting how the patient is responding to TAC as a function of time. The exact dose administered as well as any clinical event at that time is also depicted, unique only to PKB. Figure 2, illustrates the patient history component of the TAC DB. Customizable biomarkers, such as ALT, AST and SRCR are graphed together on one screen along with the TAC concentration over a defined period of time. Figure 3 depicts our latest DB, the Oncology Therapy DB. It provides information on the various drugs prescribed for a given therapy, relevant lab values as well as graphical views of relevant biomarkers providing a more holistic view of drug-therapy management within a common treatment modality

### Past year's Accomplishments

- National Library of Medicine (NLM) grant filed
- Initial TAC DB developed/functional
- Prepared grant resubmission strategy based on NLM grant review
- Manuscript on PKB concept accepted
- · 5 Video vignettes filmed and populated to PKB website
- PKB presented at Therapeutic Drug Monitoring Mtg at Nice, France
- Initial Oncology Therapy Dashboard developed
- Developed questionnaire to assess CHOP dosing practices and completed survey for baseline PKB assessment (*results below*) <u>Ongoing Efforts</u>
- MTX Dashboard Clinical & Software Validation 1/2008
- PKB concept to be presented at HEXAL Meeting in Frankfurt, Germany -2/2008
- Model / Clinical / System Validation of Oncology Therapy Dashboard ongoing
- Resubmission of Thrasher / NLM Grant 5/2008

### Pediatric Pharmacotherapy Questionnaire

Analysis of the results are ongoing with a manuscript to be submitted in 1Q '08  $\,$ 

# A total of **315** Physicians, Nurses and Pharmacists responded to the questionnaire

• Almost **80%** of the responders considered dosing adjustment to be extremely important in Pediatric Pharmacotherapy

• Nearly **75%** of the responders would like to have access to a predictive tool that would allow them to individualize patient treatment  $\rightarrow$  P.K.B

# Results





### Figure 2 : Patient History (TAC)



### Figure 3 : Oncology Therapy Dashboard



### Conclusions

•The Oncology DB design will permit a broader view of the complex poly-pharmacy that exists when managing children with cancer on various chemotherapy regimens on top of the myriad of other agents they take to manage other complications due to their condition

•The ongoing clinical validation of the MTX DB suggests that the implementation of this dashboard design will improve MTX management by faster recognition of patient outcomes associated with MTX pharmacotherapy

•The marketing/funding strategy launched in 2007 included international presentations made showcasing PKB and soliciting commitment to test prototypes. An external advisory board composed of international thought leaders is enthusiastic about the concept and global integration.



# Sudden Cardiac Death Prevention Program

Youth Heart Watch at CHOP

# An affiliate of Project ADAM®

Jan 2008

A Department of Pediatrics Chair's Initiative

## **Project Goals**

v Youth Heart Watch at The Children's Hospital of Philadelphia, an affiliate of Project ADAM®, was established to facilitate prevention of Sudden Cardiac Death in children and adolescents.

Youth Heart Watch is committed to making automated external defibrillators available to all children and adolescents by being a resource for implementing pediatric public access defibrillation programs, as well as working toward eradicating sudden cardiac death in children through research, education and prevention initiatives.

# Implementation/Accomplishments

Developed Advisory Board with bimonthly meetings.

· Sent out press release announcing Youth Heart Watch at CHOP & had a kick off of Youth Heart Watch with media on 2.12.07 at Frankford High School.





 Designed and implemented Youth Heart Watch webpage within CHOP website to provide information on the program and on sudden cardiac arrest and its causes. Website was launched on 2.24.07.

Long QT Website implemented.





Partnered with AED Program Coordinator C-P-A-T Network (CRR/AED Public Awareness Training), Joe Russell to train a total of 250 staff at 23 schools

· Presented Greenfield Elementary School, winner of the PASNAP AED raffle, with their new AED on 6.8.07.





Working with Marcus Owens, President of Daniel E. Rumph II Foundation, to conduct screenings in the community. Dr. Vetter received the "Bright Star" Award at the 2nd Annual Daniel E. Rumph II Foundation Gala

- Youth Heart Watch is mentioned
- in Good Housekeeping September, 2007 Issue.
- Met with Delaware Department
- of Education re: a feasibility study
- to require all high school students

to be certified in CPR/AED before graduation;

Met with Delaware Division of Public Health re: DE's First State First Shock Program.

· Presented Abington High School with their new AED on January 14th, 2008.

Working with the Government Affairs and Community Relations department at CHOP on key legislation to help prevent sudden cardiac arrest/death. House Bill 1789 introduced. Bill to be introduced soon for AED mandate in all schools and school related recreational fields for children.

# Implementation/Accomplishments

Working with the marketing department to develop an informative video for legislators and various organizations to provide them with information about Youth Heart Watch at The Children's Hospital of Philadelphia, the need for AEDs in schools, information about sudden cardiac arrest and how they can help. A second video is being created specifically for schools to discuss public access defibrillation program implementation. In addition to the two videos, several PSAs are being created as well as a Youth Heart Watch manual for schools to follow for starting and sustaining their program.

Youth Heart Watch featured in CHOP 2007 Annual Report.



midst of the game, the unthinkable occurs a child's heart stops. In three min Life ebbs away. A bright future disappet A family begins the journey of grief.

It's a beautiful fall day on a soccer field. In the



mate calls 911. The principal us a portable defibrillator And a heart beats again.p

Or, a teacher begins CPR.

Youth Heart Watch is a part of the HEART Safe Philadelphia Coalition-Helping to increase sudden cardiac arrest awareness and bystander CPR in Philadelphia.

Attended the PSAHPERD Convention as an exhibitor on November 16th and 17th-Raffled off an AED for one school.

Youth Heart Watch teamed up with Parent Heart Watch and Hoops for Heart Health to conduct a CPR Awareness Night on December 12th at the 76ers-Timberwolves NBA game

Co-hosting the Inaugural "Holes for Hearts" Golf Outing on June 26, 2008 with the Daniel E. Rumph II Foundation.



### **Baseline Performance Measures**

- Schools contacted: Have served 81 Pennsylvania schools 19 New Jersev schools
  - 41 Delaware schools
- Funds raised for AEDs and School
- Training Grants
- Vumber Youth Heart Watch Schools Number AEDs placed
- Number of Training Grants Awarded (27)
- Number of People Trained
- Previous vears goals met

### Open Issues: In Process

- Develop YHW database with PING
- Develop school curriculum for CPR and AED education
- Complete YHW Pamphlet for Schools
- Resubmit Medtronic Grant to fund Training Grants

# Next Steps

. Continue to meet with schools to aid in developing and sustaining their automated external defibrillation program. suggest sources of funding for AEDs, and aid schools in implementing a high school curriculum to teach every high school student CPR and AED use.

. Help pass Bill in PA House and Senate to mandate school AEDs.

Victoria L. Vetter, M.D. vetter@email.chop.edu

The Children's Hospital of Philadelphia 215-590-3529 Jan 29, 2008



lfamily

# Sudden Cardiac Death Prevention Program

Heart Health Screening Study

A Department of Pediatrics Chair's Initiative

### **Program Goals**

♥ Conduct a research study to evaluate the feasibility of ECG screening of 400 children to identify those at risk for sudden cardiac death from arrhythmias associated with hypertrophic cardiomyopathy (HCM), other structural and functional defects, ARVD, coronary artery anomalies, and primary electrical disease (Long QT Syndrome, Brugada, CPVT, WPW).

 Propose a legislative mandate for universal heart screening in children

### Background

Sudden cardiac arrest or death (SCD) is associated with structural heart disease, and primary electrical abnormalities in the heart. In children, SCD is associated with structural and electrical cardiac abnormalities including hypertrophic cardiomyopathy, long QT syndrome, coronary artery anomalies, congenital heart defects, and Wolff-Parkinson-White (WPW) syndrome resulting in up to 7,000 childhood deaths yearly in the US. No large studies have screened school children in the US for SCD to identify those at risk and to prevent death. Limited data suggest that ECG screening is more sensitive in identifying those at risk for SCD than history or physical exam. Data from other countries with mandatory ECG screening have demonstrated that ECG screening can identify children with undiagnosed conditions predisposing to SCD.

# Implementation/Accomplishments

Submitted R-01 application for multi-center study of 50,000 to 100,000 children nationally

Completed enrollment of 400 subjects

Presented abstract at AHA Nov 2007 and 2 CME courses

 Screened 700 children in Plymouth Whitemarsh Township School District

 Supported 3 rising 2<sup>nd</sup> year medical students in related research projects with publication in progress

 Screened 50 children in Madison Square Garden at Maggie Dixon Clinic in collaboration with CARE Foundation

 Working with NY City Mayor's Office on potential screening of 100,000 NYC school children

### Methods for National Study of Heart Health Screening in Youth (Ages 5-19 yrs)

Screen 25,000 young people ages 5-19 years with ECG

10 National Centers interested in participating

 Personal Medical History and Family History Questionnaires including elements of Preparticipation Screening (PPS) Form
 Cardiac Exam including elements of physical exam, blood pressure measurement, and body mass index (BMI)

 Echocardiography Screen of the 5-10% who have abnormal ECG, positive family history or positive personal medical history plus 5000 at CHOP

Referral of subjects with abnormal findings to cardiology specialist
 Collection and analysis of data

 Use of data to recommend universal screening and determine best age(s) for screen, methodology (ECG/ECHO), predictive PPS questions, and logistics of referral of positive screens to specialists



Victoria L. Vetter, M.D.	The Children's Hospital of Philadelphia				
vetter@email.chop.edu	215-590-3529	Jan 29, 2008			

A 2006 storyboard is available upon request.

# The Chair's Initiatives Inventory of Available Material

To request copies of any of these items, or items from the preceding pages, contact the Department of Pediatrics at 215-590-2770 or marx@email.chop.edu. This information will also be available on the Chair's Initiatives Intranet site.

### Chair's Initiatives

1. Summary storyboards, 2006 and 2007

### Access Nurse Advisor

1. "Coordinated Access: Navigating the Healthcare Journey," poster, National Initiative for Children's Healthcare Quality conference, 2007

2. "A Guardian of Good Care," *Children's View* magazine (CHOP), fall 2006

3. Galaxy Guest Book

# Referring Physician Communication and Care Coordination

1. "We Hear You," poster, National Initiative for Children's Healthcare Quality conference, 2008

2. We've Got News for You! flyer for referring physicians

3. Care Binder: A Quick Guide

4. "Care Binders Make Life a Little Less Chaotic," CHOP Family News, fall 2008

5. "Care Binders Help Families Manage Avalanche of Documents," *Children's View* magazine (CHOP), fall 2008

### ADHD in Primary Care Initiative

1. List of grants and publications

Automated Appointment Reminders Project



1. "No show? Oh no!", poster, National Initiative for Children's Healthcare Quality conference, 2007

2. Material for families, including mailer/flyer and appointment cards

### Center for Bone Health

1. Strengthening Bone Health Care fact sheet

2. Caring for your Child information sheets for families



inophilie Disorder:

### Center for Pediatric Eosinophilic Disorders

1. List of publications

2. Brochure for families

Multidisciplinary Cancer Survivorship Program

- 1. List of publications and presentations
- 2. List of collaborative ongoing studies

3. "Dissemination of Multidisciplinary Model to Broader Healthcare Community" (list of visiting institutions)

- 4. "Altogether Better," CHOP Annual Report 2006
- 5. Brochure for families

### Office of Fellowship Programs

- 1. Compendium of Core Curricular Resources
- 2. Grid of curricular resources by required competencies
- 3. Presentation to CHOP Board Committee, June 2008
- 4. Presentation summarizing workforce analysis of CHOP fellowship graduates
- 5. New Fellows' Orientation agenda

### Pediatric Knowledgebase

- 1. List of publications and presentations
- 2. PKB informational flyer
- 3. PKB community fundraising initiative flyer

### Sudden Cardiac Death Prevention Program

1. List of publications and presentations

- 2. Youth Heart Watch brochure
- 3. "Keeping the Beat," CHOP Annual Report 2007

4. "Protecting Young Hearts," *Children's View* magazine (CHOP), summer 2008

5. "Gone in a Heartbeat," Youth Heart Watch video and public service announcement



# The Chair's Initiatives List of publications and presentations

Dozens of publications and presentations have resulted from the Chair's Initiatives. Here is a list.

### Access Nurse Advisor

### Presentations at external conferences

"Coordinated Access: Navigating the Healthcare Journey," M. Lizzi, A. Marx, M. Rodi, M. Chilkatowsky, T. McCall, J. Beliveau, National Initiative for Children's Healthcare Quality, 2007 conference

### ADHD in Primary Care

### Publications

Kostanecka, A., Power, T., Clarke, A., Watkins, M., Hausman, C., & Blum, N. (2008). Behavioral health screening in urban primary care settings: Construct validity of the PSC-17. *Journal of Developmental and Behavioral Pediatrics*, 29, 124-128.

Power, T. J., Mautone, J. A., Manz, P. H., Frye, L., & Blum, N. J. (2008). Managing ADHD in primary care: A systematic analysis of roles and challenges. *Pediatrics*, 121, e65-e72.

Power, T. J., Jones, H. A., Mautone, J. A., & Blum, N. J. (in press). Partnering to achieve school success: A collaborative care model of early intervention for attention and behavior problems in urban contexts. In B. Doll, W. Pfohl, & J. Yoon (Eds.), *Handbook of youth prevention science.* 

#### Automated Appointment Reminders

#### Presentations at external conferences

"No show? Oh no!: Improving Patient Access by Reducing No-show Rates," L. Barnes, E. Drames, D. Hicks, M. Kelly, National Initiative for Children's Healthcare Quality, 2007 conference

#### **Center for Pediatric Eosinophilic Disorders**

#### **Publications**

Spergel, JM, Brown-Whitehorn, TF, Beausoleil, JM, Shuker, M, Verma, R and Liacouras, CA. Natural History of Eosinophilic Esophagitis: 14 years of follow-up, *Pediar*, *Gstro Nutrition* (in press)

Spergel J, Shuker M. Nutritional Management of Eosinophilc Esophagitis. *Gastrointest Endosc Clin N Am.* 2008 Jan ;18 (1):179-194. Liacouras C. Pharmacologic Treatment of Eosinophilic Esophagitis. *Gastrointest Endosc Clin N Am.* 2008 Jan ;18 (1):169-178 18061110 (P,S,E,B,D)

Spergel J, Brown-Whitehorn, T. Eosinophilic Esophagitis: Clinical update. *Pediatric Health. 2008 Aug;* Volume 2, number 4, pages 443-451.

Spergel, J, Brown-Whitehorn T, Beausoleil J, Shuker M, Liacouras C. Predictive values for skin prick test and atopy patch test for eosinophilic esophagitis. *Journal of Allergy and Clinical Immunology*. 2007 Feb; Volume 119, Issue 2, Pages 509-511.

Heltzer, M, Franciosi J, Shuker M, Liacouras C, Spergel J. Demographic Information for Patients with Eosinophilic Esophagitis. *Journal of Allergy and Clinical Immunology.* Volume 119, Issue 1, Pages S111-S111.

Spergel J. Eosinophilic esophagitis in adults and children: evidence for a food allergy component in many patients. *Current Opin Allergy & Clinn Immunol.* 2007 Jun; 7(3):274-278. Review.

Furuta GT, Liacouras CA, Collins MH, Gupta SK, Justinich C, Putnam PE, Bonis P, Hassall E, Straumann A, Rothenberg ME. Eosinophilic Esophagitis in Children and Adults: A Systematic Review and Consensus Recommendations for Diagnosis and Treatment Sponsored by the American Gastroenterological Association (AGA) Institute and North American Society of Pediatric Gastroenterology, Hepatology, and Nutrition. *Gastroenterology*. 2007 Oct ;133 (4):1342-1363 17919504 (P,S,E,B,D)

Liacouras C, Bonis P, Putnam PE, Straumann A, Ruchelli E, Gupta SK, Lee J, Hogan SP, Wershil BK, Rothenberg ME, Ackerman SJ, Gomes I, Simon Murch, Mishra A, Furuta GT. Summary of the first international gastrointestinal eosinophil research symposium.*J Pediatr Gastroenterol Nutr.* 2007 Sep ;45 (3):370-91 17873754 (P,S,E,B,D)

### Multidisciplinary Cancer Survivorship Clinic

#### **Publications**

Hobbie WL, Moshang T, Carlson CA, Goldmuntz E, Sacks N, Goldfarb SB, Grupp SA, Ginsberg JP. Late effects in survivors of tandem peripheral blood stem cell transplant for high-risk neuroblastoma. *Pediatr Blood Cancer.* 2008 Nov; 51(5):679-83.

Carlson CA, Hobbie WL, Brogna M, Ginsberg JP. A multidisciplinary model of care for childhood cancer survivors with complex medical needs. *J Pediatr Oncol Nurs.* 2008 Jan-Feb;25(1):7-13.

Ginsberg JP, Ogle SK, Tuchman LK, Carlson CA, Reilly MM, Hobbie WL, Rourke M, Zhao H, Meadows AT. Sperm banking for adolescent and young adult cancer patients: sperm quality, patient, and parent perspectives. *Pediatr Blood Cancer*. 2008 Mar;50(3):594-8.

Ogle SK, Hobbie WL, Carlson CA, Meadows AT, Reilly MM, Ginsberg JP. Sperm banking for adolescents with cancer. *J Pediatr Oncol Nurs*. 2008 Mar-Apr;25(2):97-101.

### Presentations at external conferences

### Oral presentations

Ginsberg JP. Sperm Banking: Development of an Improved Clinical Practice. 9th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Niagara-on-the-Lake, Ontario, Canada, June 2006.

Carlson, CA. A multidisciplinary model for long-term survivor care. The Second International Nursing Conference on Childhood and Adolescent Cancer Survivorship, Niagara-on-the-Lake, Ontario, Canada, June 2006.

### **Office of Fellowship Programs**

### Publications

Balmer DF, Lisby DA, Harris MC, Slap GB. Do pediatric fellows recognize the importance and contribution of training to mastery of the general competencies? *Medical Teacher* 2008; In Press.

Slap GB, ed. *Requisites in Pediatrics. Adolescent Medicine.* Philadelphia: Elsevier, 2008, 330 pp.

### Presentations at external conferences

Balmer DF, Lisby DA, Harris MC, Slap GB. Do pediatric fellows recognize the importance and contribution of training to mastery of the general competencies? Abstract presentation at the Pediatric Academic Societies' Annual Meeting, Toronto, 5/8/2007

### Pediatric Knowledgebase

### Publications

Barrett JS, Mondick JT, Narayan M, Vijayakumar K, Vijayakumar S. Integration of Modeling and Simulation into Hospital-based Decision Support Systems Guiding Pediatric Pharmacotherapy. *BMC Medical Informatics and Decision Making* 8:6, 2008.

Barrett JS, Patel D, Jayaraman B, Narayan M, Zuppa A. Key Performance Indicators for the Assessment of Pediatric Pharmacotherapeutic Guidance. *The Journal of Pediatric Pharmacology and Therapeutics* 13:3, September 2008

### Presentations at external conferences

"The In Silico Child" at joint meeting of the American College of Clinical Pharmacology (ACCP) and the Association for Applied Human Pharmacology (AGAH), Dusseldorf, Germany, February, 2006 "Modeling and Simulation Approaches for Compound Progression of Antiretroviral Agents" at HIV Preclinical -Clinical Therapeutics Research Meeting, May 15-16, 2006, Bethesda, MD (sponsored by NIMH and NIAID)

"Pediatric Knowledgebase: A Hospital-based, informatics Approach to Improve Pediatric Patient Therapeutics" at The Children's Hospital of Philadelphia's Pharmacologic Basis of Pediatric Therapeutics Research Affinity Group Summer Symposium, "Clinical Pharmacologic Intervention into Pediatric Clinical Research: Informative Designs, Approaches and Informatic Integration," July 19, 2006

"Quantitative Pharmacology in a Translational Research Environment" at the AAPS/ACCP Joint Symposium: Quantitative X-ology: An Overarching Theme in Critical Path Drug Development, AAPS Annual Meeting 2006, San Antonio, TX, October 31, 2006

"Evolving Relevant Data Signatures for Compounds Utilized in Pediatric Pharmacotherapy: M&S Approach to Translational Research," Clinical and Formulation Considerations in Designing Pediatric PK/PD Studies at the AAPS Annual Meeting 2006, San Antonio, TX, October 31, 2006

"Design and Implementation of a Paediatric Knowledgebase: A Decision Support Interface to Guide Patient Pharmacotherapy," PKUK 2006 Meeting, Sheffield, England, November 17, 2006

"Design and Implementation of a Pediatric Knowledgebase: A Decision Support Interface to Guide Patient Pharmacotherapy," in the "Contemporary Therapeutic Drug Management: Integrating patient information, pharmacogenetic testing, PK model-based TDM and Informatics to Improve Clinical Care" session, March 23, 2007, ASCPT Annual Meeting, Anaheim, CA.

"Integrating Modeling and Simulation Strategies into Targeted Translational Research," International Symposium on Quantitative Pharmacology in Drug Development and Regulatory Sciences, Nanjing, China, Oct 28-31, 2007 (http://www.qpharmmeeting.com/).

### **Referring Physician Communication**

### Presentations at external conferences

"We Hear You: Incorporating Primary Care Feedback into Subspecialty Care," J. Beliveau, M. Chilkatowsky, M. Lizzi, A. Marx, T. McCall, M. Rodi, National Initiative for Children's Healthcare Quality, 2008 conference

### Sudden Cardiac Death Prevention Program

### Publications

Vetter VL, Dugan NP, Vogel L, Mercer-Rosa L, Gleason MM, Cohen M. Heart Screening for Sudden Cardiac Arrest in Healthy Children. *Circulation* 116:II\_663, 2007.

Myerberg RJ, Vetter VL. Electrocardiograms should be included in preparticipation screening of athletes. *Circulation* 116:2616-2626, 2007.

Vetter VL. Role of ECG Screening in Evaluation of SCA Risk. *Pacing & Clinical Electrophysiology*. In Press, 2008.

### Non-peer reviewed publications

"Youth Heart Watch Program Marks First Year of Saving Lives," *El Hispano*, March 2008

### "Heart Help," Good Housekeeping, Sept. 2007

### Presentations at external conferences

"Mentoring the New Pediatric Cardiologist," American Heart Association Annual Scientific Session 2006, Chicago, IL, Nov. 2006

"Device Therapy in Children and Adults with CHD" – Chair, Oral Abstract Session – 28th Annual Scientific Sessions Heart Rhythm 2007, Denver, CO, May 2007

"Prevention of Sudden Cardiac Death in Young Athletes" – CME Lecture, The University of Washington School of Medicine, Seattle, WA, January 2008

"Can We Better Identify Children and Adolescents at Risk?" Emergency Cardiovascular Care Update – ECCU 2008, Citizen CPR Foundation, Las Vegas, NV, June 2008

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