



Spring/Summer 2004

**M A T T E R S**

The Newsletter of the Children's Hospital at Dartmouth

**CHaD's  
Child  
Life  
Program**



# Treating the “Inner Self”

**W**HEN LINDA JARVIS CAME TO DHMC in 1987, the concept of holding a summer camp for kids with arthritis was still new. “There were only six arthritis camps in the country back then,” she says. “Now there are better than twenty five.”

Camp Dartmouth-Hitchcock (D-H), begun in 1983, has played an important role in this growth. “Because of our experience and our close collaboration with the American Juvenile Arthritis Organization and the Arthritis Foundation Chapters, we’ve been able to share what we’ve learned to help other regions launch their own camps,” says Jarvis, administrative assistant in Rheumatology who continues to handle administrative duties for Camp D-H each year.

## Building a Sense of “I Can”

This August will mark Camp D-H’s twenty-first year of operation. It is designed to provide children (ages 8-14) with juvenile rheumatoid arthritis (JRA) and other rheumatologic diseases a camp experience that facilitates lasting personal growth and independence. The cost of the one-week residential camp, which will once again be held at the Hulbert Outdoor Center on Lake Morey in Fairlee, VT, is \$450 per camper.

“It’s an ideal setting for children to enjoy traditional camping activities such as swimming, canoeing, arts and crafts, and outdoor games,” Jarvis explains. “As importantly, it gets them out of isolation. It’s very common for these children to be the only ones with JRA in their schools, and their lives can become quite sheltered.”

Each child’s communication and problem-solving skills are challenged through a series of structured activities, such as the Camp’s rope course. They are taught how to communicate their needs and work with others to solve complex physical tasks. Senior campers, ages 15-16, learn leadership skills while acting as role models for younger campers.

“It’s very effective,” says Jarvis. “We know by the surveys we receive back from parents and caregivers that the experience really helps to build their self-esteem. These are kids who often struggle with simple tasks such as combing their hair, writing, and tying their shoes. When they leave us, they tend to be much more willing to try harder to do for themselves.”

## Dedicated, Caring Staff

One of the keys to Camp D-H’s success is the caring, dedicated nature of its staff. “We have a wonderful staff



of committed professionals including volunteers from CHaD and from our community who donate a week of their personal vacation time each summer for the kids,” she says. The arthritis faculty includes doctors, nurses, physical therapists, occupational therapists, social workers, and medical students.

“In addition, the Hulbert facility’s staff really understands our needs,” she says. “They provide ramps and install other assistive aids to provide as much ease of mo-

bility for the kids as possible. The Lake Morey Country Club even loans us a golf cart for transporting some children to and from activity locations.”

Though the camp has received requests to expand, Jarvis says it’s unlikely that it will change its one-week format. “We’ve grown to the point where we can accept about 40 kids during the third week of August each year, and that’s manageable,” she says. Meanwhile, the concept continues to grow elsewhere.

“One of our camp ‘graduates’ from Canada, now a Fellow in rheumatology at Montreal Children’s Hospital, came back to volunteer summers ago,” Jarvis says. “She is establishing a JRA camp there based on our model. It was wonderful to see her, and gratifying to know that the work of so many people over the years continues to make a difference.”

# Donations to Support Expansion of Craniofacial Clinic Services

**T**HE BIRTH OF A CHILD WITH A craniofacial deformity can be emotionally devastating for a family. Without treatment, abnormally formed facial features can stigmatize a child and profoundly affect his/her social and psychological development.

“The process of growing up presents many challenges for any child, but especially so for a child born with a major facial deformity,” says Dr. Mitchell Stotland, director of Pediatric Plastic Surgery at CHaD, and medical director of the Craniofacial Clinic/Face of a Child Program. “For a child to live with no ear, or a lip that naturally rests in a ‘snarling’ position or with the inability to speak with a normal vocal resonance, the process of growing up—not to mention succeeding socially as an adult—can be much more difficult. Our goal is to remove that burden from an individual’s life.”

## Multidisciplinary Approach

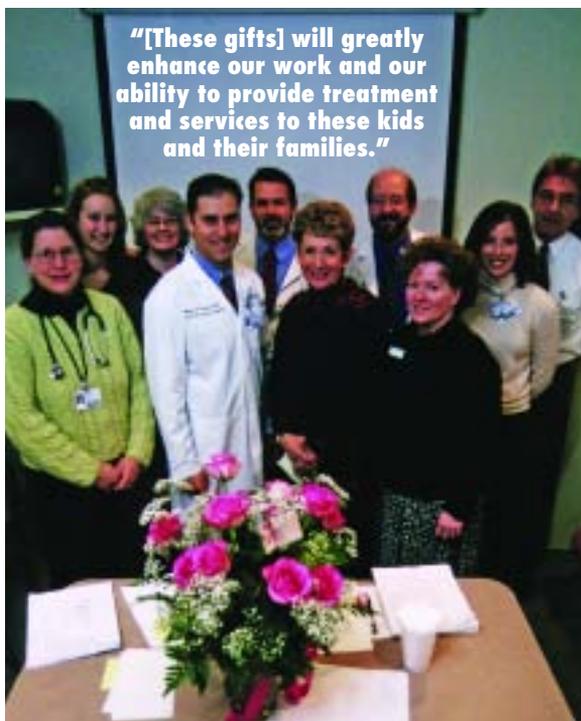
Since children with craniofacial anomalies may require care from a variety of specialists, the clinic draws upon the skills of providers from many areas of expertise within CHaD including audiology, genetics, neurosurgery, oral surgery, orthodontics, otolaryngology, plastic surgery, and speech pathology.

“By working collaboratively and organizing the delivery of care into a single multidisciplinary clinic, our team strives to provide children and families with highly specialized treatment combined with a personalized and caring approach,” says Stotland. “With the addition of a clinic coordinator, we will be even better positioned to do that.”

## Funding for New Position

Thanks to generous gifts made by WalMart stores throughout New Hampshire and private donor Carla Manley, the clinic has created a permanent coordinator’s position this year to provide essential support to the services we provide to children born with all varieties of craniofacial disorders.

“These gifts are wonderful and tremendously appreciated,”



**Dr. Mitch Stotland and Carla Manley (front and center) stand with the Craniofacial Clinic staff.**

says Stotland. “They will greatly enhance our work and our ability to provide treatment and services to these kids and their families.”

Set up as an endowment to help fund the clinic’s services for years to come, Mrs. Manley’s gift will begin providing support for the new position in 2005. “I’m very excited and proud to be able to contribute to this important need,” says Manley, a former pediatric nurse and Board member of the Friends of CHaD.

“Mitch’s compelling presentation at our board meeting several months ago, which demonstrated both how children’s lives can be transformed through these services and the clinic’s very real need for additional support, inspired this gift,” she says.

## Getting Started

According to Stotland, the WalMart gift provides the first-year funding that was needed to establish the coordinator position in 2004. “I’m delighted to report that we’ve hired someone who we feel is ideally suited for the position,” he says.

Belinda Ray, who assumed her new duties in April, has an extensive background in psychiatric services and has been coordinating a research project for Stotland since last July. “I’m very passionate about this position,” says Ray. “I think the work that the clinic is doing is very important. Every case is unique and can be quite complicated for patients and their families. As the program coordinator, it’s rewarding to be able to make that process easier for them.”

The WalMart donation comes on the heels of another successful year of fundraising undertaken by the company to support a variety of programs and services at CHaD. “Their committed generosity and passion for the children’s hospital has been overwhelming,” says Sharon Brown, director of community relations for CHaD.

“Our ability to utilize this corporate funding, together with Carla’s generous gift, will help us to ensure that the great work Mitch and the entire Face of a Child team is doing to meet the special needs of these patients is not only enhanced, but also sustained over the long-term,” she says.

# CHaD Prepares to Open New Family-Centered Outpatient

LATER THIS SUMMER, CHAD WILL OPEN the doors to its eagerly-anticipated Outpatient Center. The new child-and-family-focused space, which will provide 46 pediatric exam rooms and nearly as many offices for physicians and staff, will handle virtually all of CHaD's outpatient activity.

"We're very excited about it," says Kevin Donovan, director of CHaD's ambulatory services and coordinator for the project. "Most likely, the move to our new space will take place in early August. Combining all of the specialty areas that will be involved, we expect to handle approximately 55,000 patient visits in our first year."

## Community Helps Shape Design

The opening of the new clinic space will represent more than two years of research and intensive planning that included conducting focus groups with patients and parents and making a site visit to Hasbro Children's Hospital in Rhode Island.

The project's multidisciplinary interior design committee—comprised of clinicians and staff, community members and space planners—also presented its plans at many hospital staff meetings and in front of other CHaD-affiliated groups to get their feedback.

"One of the important realizations from our discussions was that not all families fit one description," says Kirsten Murphy, who provided a parent's perspective as a member of the committee. "I like that we were able to design multiple waiting areas to meet the different needs of urgent, well-child, and specialty care visits. If you're a mother who's bringing your baby in for a checkup, you'd rather not have them surrounded by kids with the flu."

The committee took the concept one step further in designing a quiet space for families with special needs. "I think it's wonderful," says Murphy. "I have an autistic son and know how easily he can become over-stimulated and frightened. Having a space that is separate from other activity

will really help to make visits more calming for children like mine and their families."

## Family-Friendly Waiting Areas

One of the biggest advantages the new space will offer families is its centralized location. "Instead of having to go to different parts of the hospital to receive different outpatient services, most families will now go to one location," says Donovan. "And since they will use the new parking garage, they'll be able to access the clinic without having to walk outside."

Upon entering the clinic, patients and their families will be treated to spacious waiting areas filled with natural light. "It's going to be a physically beautiful space," says Lorraine Guile, president of Quechee Lakes Land Owners Association (QLLA) Charities, a major supporter of the new clinic. "The colors and artwork that were chosen are consistent with a natural, aquatic theme that coincides with other CHaD spaces. Our goal was to create a reassuring and comforting atmosphere for visitors."

A number of interactive play and viewing stations—from "I-spy" windows, a kaleidoscope and a computer station to an Aeolian landscape (wind/sand) device, decorative chairs and "hi-spy" viewing machines—will be positioned throughout the waiting areas. "We collaborated with the Montshire Museum to create stations in each of the three main waiting areas to provide fun activities for the children to enjoy," explains Donovan.

The committee considered function as well as comfort when designing the waiting areas. "We went to great lengths to choose the kind of flooring and fabrics that would be safe and easy to keep clean," he says. "We've also incorporated shared seating areas, so that parents can cuddle with their children if they want to."



**"Our goal was to create a reassuring and comforting atmosphere for visitors."**

## Bringing Physicians, Staff Together

A key benefit of the new ambulatory space for CHaD providers will be its consolidated service area. "For the first time, most of our pediatric specialists, generalists, and staff will all be located on one floor," says Donovan. "Physicians will not only be in close proximity to their staff, they'll also be contiguous to one another, where more frequent interaction and informal exchange of ideas can occur."

In addition to being specifically designed and equipped for pediatric patients, the clinic's exam rooms will be on average

# W, Clinic

## CHaD Family Center to Move to New Clinic Space



20 percent larger than current space. “This will be a big plus,” says Susan Whitcomb, RN, a pediatric nurse. “Oftentimes, when a patient comes into the exam room they’re accompanied by other family members, so having the extra space will be nice.”

Whitcomb says her fellow nurses in general academic pediatrics are looking forward to moving to their new home. “We’re very excited about joining the other pediatric specialty areas,” she says. “It will be great to be working together in a dedicated space that is designed around meeting the needs of children and their families.”

**W**hen patients and families enter the new CHaD Outpatient Center, slated to open in late July, one of the first things they will encounter is the new CHaD Family Center.

The Center will move from its current location in the medical center on 3 East to become part of the soon-to-open outpatient space that will combine virtually all of CHaD’s primary and specialty care units. “In the new setting, we’ll be better positioned to provide the variety of support services that we’re able to offer to families,” says Antonette LaMonica, manager of the Boyle Community Pediatrics Program.

Over the past year, the CHaD Family Center—created by parents who saw the need for greater access to community resources to help them manage chronic conditions—has been primarily inpatient-focused. “Because of our location, not many families outside the inten-

sive care units have been aware of us,” says LaMonica. “As much as we’ve enjoyed being here for them, we recognize the need to extend our services.”

### More Space, Resources

According to Robin Goodrich, resource specialist and coordinator for the CHaD Family Center, the new space will be significantly larger. “It will be four times bigger than what we have now,” she says. “That will give us the ability to accommodate many more families at one time.”

Rachel’s Corner, named after a pediatric patient and member of the family fac-

ulty who died two years ago, will be expanded to include a loft, additional play space, and an activity center where kids can participate in art projects and story hours. The space will also serve as a meeting spot for Camp CHaD, a program that offers play breaks twice a day for children staying in the hospital.

The new CHaD Family Center will have a teen corner and two computer stations offering public internet access, as well as email for parents to check in with their employer. “We hope to expand our pediatric consumer health library which offers web-based health information and a specialized collection of books on chronic illnesses and disabilities,” Goodrich says.

“We’re in the process of ordering some additional furniture, so families will also have a comfortable spot to take a break and relax between appointments,” she says.

### A Bridge to the Community

The larger space and new location will allow the Center to fulfill its central role as a bridge between existing hospital departments and the surrounding community, says Kirsten Murphy, a parent who sits on the CHaD Family Center’s Advisory Council and has been closely involved in the Center’s development.

“I talk to a lot of families who have disabilities,” says Murphy, who is the parent of an autistic child. “One of the most frustrating things for parents is to learn about a diagnosis, but not know what to do about it,” she says. “This Center will go a long way in not only informing families about resources but also in connecting them to those who can best help them.”

In addition to offering one-on-one assistance from a resource specialist, the Center will provide a community space for support group meetings as well as a place for parents to meet with local agencies such as Parent to Parent, an organization of parents offering support and information to parents of children with special healthcare needs.

“Everything in the CHaD Family Center is based on the generosity of donors and parents,” says LaMonica. “We’re very grateful for that, and we’re very excited about the opportunities that the new space will give us to help even more families in the future.”

# Pediatric Pulmonology Program Rejuvenated

**T**HOUGH A STRONG foundation for excellence had been established for pediatric pulmonology at CHaD, the program had lost a bit of its momentum in recent years.

“Dr. John Brooks’ unexpected departure following a serious automobile accident left a real void,” explains Lynn Feenan, RN, a clinical nurse specialist and nine-year veteran of the program. “We were fortunate to have Dr. Steve Grandgeorge from the clinic in Manchester here on a part-time basis, but we lacked the full-time expertise needed to push our program forward.”

That all changed when Dr. Dennis Stokes came to Lebanon. Since his arrival last July, Stokes has been helping to direct the efforts of CHaD’s well-integrated team of researchers and clinicians who are working to find more effective treatment modalities for pediatric patients suffering from pulmonary diseases.

## Leading Expertise in CF

Dr. Stokes specializes in the diagnosis and management of Cystic Fibrosis (CF)—a chronic, progressive, and frequently fatal genetic disease of the body’s mucous glands that primarily affects the respiratory and digestive systems in children and young adults.

“CF is a complicated illness,



and we’re probably years away from finding a cure,” says Stokes. “But by consistently applying evidence-based patient care, we can make significant improvements in both the quality of life and life expectancy of patients.”

Before coming to CHaD, Stokes was professor of pediatrics at the Indiana University School of Medicine. His leadership experience includes serving as director of the Vanderbilt CF Evaluation and Treatment Center in Nashville, and as associate director of the CF Center at the Johns Hopkins Hospital in Baltimore.

## Sharing Data to Improve Care

A major reason Stokes was drawn to CHaD was DHMC’s involvement in the Northern New England Cystic Fibrosis

Consortium, which includes 80 clinicians and more than 460 patients across five sites in Maine, New Hampshire, and Vermont. Led by principal investigator Dr. Gerald O’Connor, the consortium’s mandate is to share data, develop guidelines for approaching clinical problems, and create con-

**“By consistently applying evidence-based patient care, we can make significant improvements in both quality of life and life expectancy”**

sensus about the best way to provide care.

“Gerry is a national leader in terms of changing the way CF care is delivered and incorporating clinical improvement into CF centers,” says Stokes. “If we can just do as well as the best centers in the country, we can add five to seven years to patients who are now living an average of 33 years.”

Quality improvement has been a major interest of Stokes’ for some time. He recently enrolled in a microsystems class at Dartmouth’s Center for Evaluative Clinical Sciences (CECS), and has eight hours of coursework remaining to complete a master’s degree in public health.

“It’s a dream come true for me to be able to integrate quality improvement into day-to-day clinical care,” he says. “I hope to use QI to optimize our interactions and workflows when we

move to the new CHaD Outpatient Center in July.”

## Bringing Parents to the Table

According to Stokes, one of the most important developments for the program is the inclusion of parents in the quality improvement process. “When parents are at home taking care of their child, they devise strategies to help them remember when to do the treatments and how to get their child to take their medication,” he says.

Feenan, who spends much of her time working with home nursing agencies, schools, and equipment vendors to coordinate care for families, agrees.

“One of the things that can be very effective is for parents to teach other parents what has worked for them,” says Feenan.

This can be critical when it comes time for children to start attending school. “I spend a lot of time working with parents, and helping to educate teachers and school staff about chronic illnesses,” she says. “Making sure that schools are comfortable with a diagnosis and plan of care can make all the difference.”

One of Stokes’ innovations has been to hold regular pulmonary case videoconferences with other leading children’s hospitals—bringing together teams of clinicians—to discuss patients with uncommon pulmonary disorders like Caleb Nelson, who has central hypoventilation syndrome. “Part of our obligation to families like Caleb’s is to connect them with some of the best experts in the world,” he says. “It’s also good for our residents to hear how other centers approach uncommon pulmonary problems.”

## From Bench to Bedside

With no cure for chronic illnesses like CF in sight, Stokes believes that focusing on clinical improvements is the key to advancing patient care.

“In the mid-90s, everybody saw gene therapy as the answer,” he says. “But, it’s become clear that achieving that is much more difficult than people realized.”

In the meantime, Stokes sees opportunities in a number of areas to improve care. “We’re looking at the emergence of bacterial resistance to antibiotics in some of our CF patients,” he says. “We’re also trying to increase our interactions between clinicians and basic science leaders like Dr. Bruce Stanton to bolster our research efforts.”

With Stokes’ expertise in pediatric bronchoscopy—the visual examination of the bronchi of the lungs using a bronchoscope—performed in conjunction with CHaD’s Painfree program, more patients are benefiting from an earlier diagnosis and treatment of their conditions. “In addition, I have a great interest in working with our sleep lab to expand our studies to include young children and infants, since they make up a significant portion of kids with sleep problems.”

“We have a great interdisciplinary team here—combining pediatric and adult CF caregivers—that works very well together and helps transition pediatric patients to adult care,” says Stokes. “We’re focused on making sure new medications and therapies that prove effective are put into practice as soon as possible, so that every patient has the chance to reach their potential.”

WHEN HEATHER NELSON GAVE BIRTH TO HER SECOND child about a year and a half ago at Cottage Hospital, the last thing she expected was to have complications. “I already had a healthy two-year-old daughter and I had enjoyed a normal pregnancy,” she explains.

But, very quickly, difficulties began for little Caleb Nelson. “During my delivery, his heart rate kept dropping,” says Heather. “When he came out, they discovered that the umbilical cord had wrapped around his neck. It took deep suction to stimulate his breathing.”

Caleb showed little interest in nursing, and developed a “stridor,” a raspy noise when breathing. “I noticed it, but the nurses didn’t seem to hear it,” Heather says.

### A Rocky Start at Home

After only being home for about three weeks, Heather noticed other changes. “When he cried, he had no voice,” she says. “And, his skin would turn grey and clammy at times. Our pediatrician was out of town, so we brought him to the local ER—they thought he had laryngitis and sent us home.”

Caleb’s symptoms continued to oscillate. “The night before we were scheduled to see his pediatrician, I stayed up the whole night to watch him. I knew something was wrong, but I couldn’t put my finger on it,” says Heather. “The next day, he fell asleep in my arms after nursing. Then he woke up choking, and stopped breathing.”

Heather called “911,” laid Caleb on the floor, and began CPR. “He took a big gasp of air, and then stopped breathing again,” she says. A few minutes later, as the ambulance sped off carrying Caleb to the Cottage ER, she stood in the driveway with her other child, still reeling from the shock of what had happened.

Heather’s husband Grant, who had been out haying on the family’s dairy farm, rushed back to accompany her to the hospital. “Seeing all of those people working on Caleb made us realize how serious his condition was,” she says. “Cottage doesn’t have a pediatric unit, so they called DHART—Caleb was intubated and they flew him to CHaD.”

### Searching for Answers

Caleb’s arrival in Lebanon marked the beginning of a close bond that would develop between CHaD staff and the Nelsons. “As soon as we got there, the nurses brought us to the intensive care unit and made sure we were OK—they really took care of us,” says Heather. In the next year, Caleb would only spend a total of two months out of the intensive care unit, as CHaD’s multi-disciplinary team of specialists worked together to identify his condition and

find more effective forms of treatment.

“Dr. Casella ran tests that revealed Caleb’s body couldn’t handle physical stressors without daily cortisol replacements,” she says. “Dr. Filiano discovered that Caleb had abnormally low levels of neurotransmitters, and a possible seizure disorder. Dr. Susan Edwards got involved because of Caleb’s problems with low mobility in his GI tract.”

### Finding a Diagnosis

Filiano—through close collaboration with colleagues at Rush Presbyterian Hospital in Chicago—identified Caleb’s disorder as congenital central hypoventilation syndrome. “It’s considered a sleeping disorder,” explains Heather. “When he goes to sleep, his natural drive to breathe slows down and he retains carbon dioxide. The

lack of oxygen puts extra strain on his heart and could potentially cause brain damage. It’s a very rare disorder—only 250 kids have been diagnosed with it.”

Caleb’s diagnosis was particularly difficult to make. “Dr. Filiano never had the complete picture of Caleb’s condition until after his first birthday,” she says. “The hard thing about Caleb’s disorder is you can only get information when he sleeps.”

Caleb has a tracheostomy and requires a ventilator when he sleeps. “He’s scheduled to have surgery soon with Dr. Gosselin, to remove scar tissue that has built up around his trach,” Heather says. “And he has to have an echocardiogram annually and a sleep study done every six months.”

### Transitioning to Home Care

“The nursing staff who help with Caleb’s care have been great,” she says. “We were approved for 96 hours of care, but less than half is covered—Caleb needs someone to watch him through the night, so I usually stay up with him a couple of nights a week. But I think we’ve turned the corner, especially now that Dr. Stokes is here.”

Dr. Dennis Stokes, a leading pediatric pulmonologist and expert in children’s sleep disorders, joined CHaD last summer. “His knowledge, experience, and personal concern for Caleb are really making a difference,” says Heather.

Since Caleb can’t tolerate a speaking valve, he prefers to communicate using sign language. “He’s a real trooper,” she says. “He’s a little behind with his speech, but he hasn’t shown any signs of neurological damage as a result of his disorder.”

“This past year has been a real rollercoaster ride for our family, with all the strains it has placed on us, financial and otherwise,” says Heather. “It’s a great relief to finally have a diagnosis, but it’s sad to know that Caleb will have this genetic disorder for the rest of his life—I’m just glad we found the people at CHaD.”

## Caleb’s Story





# Teens Face Chr

**H**OW DO YOU MEASURE THE EFFECTIVENESS OF A PROGRAM geared toward adolescents with health issues? “If the kids come back, that’s a good benchmark for success,” says Mark Detzer, PhD, a CHaD psychologist and assistant professor of Psychiatry and Pediatrics at Dartmouth Medical School (DMS).

Detzer is director of a unique program called STAR (Steps Toward Adult Responsibility) which is designed to help teens ages 13-18 with chronic illness—such as asthma, diabetes, cystic fibrosis and cancer—develop healthy coping and adjustment skills as they transition through adolescence to adulthood. Created in 1997 by Phyllis Wilson, in memory of her daughter, the

program is funded through mid-2006.

Thanks to STAR’s thorough evaluation process, which includes ongoing feedback from teens and parents, the kids almost always come back.

One such kid is John Fenley, a student at Hanover High School. With his insightfulness and engaging personality,

**“It’s so reassuring to know other parents who can truly understand what you’re going through. The support we’ve received has been tremendous—over these past four years, I’ve made lasting friendships.”**

Fenley, now a senior, has become one of the “shining lights” of STAR since he joined the program four years ago. “It’s changed my life,” he says. “From the very first day, I no longer felt like I was alone with my illness.”

## Coping with a Tenacious Condition

At only three years of age, John was diagnosed with craniopharyngioma, a rare kind of brain tumor. “We took him to Columbia-Presbyterian Hospital in New York City,” says John’s mom, Madeline Boughter. “There was no option for radiation back then, so they surgically removed the tumor.”

Though the tumor was benign, it would grow back three more times in ensuing years, causing permanent damage to John’s pituitary gland, hypothalamus, and optic nerve. “I have to take oral medications four times a day and give myself an injection every night,” he says. “It’s been a struggle for me to control my weight, since I can’t experience the sensation of being full like other people. I’m also blind in one eye.”

Amazingly, if he could turn back the clock and start over, John wouldn’t change a thing. “Even if it were possible, I don’t think I could do that,” he says. “My experiences have made me who I am, and have given me a dream to strive for—I hope to become a kindergarten teacher some day.”

# Chronic Illness with Resources

## Reaching Out, Growing Within

The STAR program offers a variety of support services to teens, including individual and group counseling, outdoor activities, and writing workshops. At the heart of the program are its monthly dinners and discussion groups, where participants can share experiences with others who face similar difficulties.

“Even though we don’t all have the same illnesses, we’ve felt the hardship and pain of living with a chronic disease,” explains John. “I always make a point of welcoming students who are new to the program—they feel awkward, especially when they’re coming for the first time.”

“Initially, I felt the same way as a parent, thinking this might not be for me,” says Madeline, about the dinner meetings STAR simultaneously hosts for parents, facilitated by Anne Baird, MSW, a pediatric social worker at CHaD. “I don’t think I’ve missed one in four years.”

“Anne and Mark have done a terrific job in creating a model that really should be available to every family that’s dealing with an ill child,” she says. “We’ve discussed issues like dealing with schools and their health offices, special educators, transitioning from high school and beyond, vocational rehabilitation services, medical insurance, and primary care physicians and their relationships with both the teen and the parent.”

“As parents, we often get so caught up in dealing with the day-to-day issues associated with our child’s illness, we run the risk of neglecting the rest of our healthy family and our spouse,” adds Madeline. “It’s so reassuring to know other parents who can truly understand what you’re going through. The support we’ve received has been tremendous—over these past four years, I’ve made lasting friendships.”

## Taking the Next Steps

John, who enjoys writing and cartooning, is working part-time with pre-schoolers at Dartmouth Day Care. He will be attending Keene State College in the fall, a transition Madeline knows may be as difficult for her as it is for her son. “Even when a healthy child leaves home for the first time, it’s often traumatic for a parent,” she says. “It’s even harder if your child has a chronic illness.”

STAR’s group mentoring program, which facilitates interaction between teenagers and Dartmouth College students who cope with similar chronic conditions, has helped to prepare John for the transition. “It’s a comfort to have friends who are already confronting what we fear...college,” he says. “When I see Dartmouth mentors ‘making it,’ I feel more ready for the future.”

“My writing mentor, Gary Maslow, helped me express the stories of my past. He was there for me when I had to relive some painful memories. Last year, my mentor Dave Shamszad, worked out with me to help me stay on track with my exercising,” he says. “He did all the exercise by my side.”

John was invited by Detzer to talk to the second-year medical school class at DMS about his condition, to present a human side to illness.

In February, he represented a teenage perspective alongside three Dartmouth College students on a panel at a medical home conference. “My illness is worth the struggle, if it means by sharing with others I can make a difference for the care of future children,” he says.

“Without STAR, I wouldn’t have found the support and resources I now have, and I don’t think I’d be going to college,” adds John. “I’m grateful for the opportunities this experience has given me.”

## Bringing Teens and Parents Together

**I**N A JOINT EFFORT THIS SPRING, CHAD and the Community Health Improvement and Benefits (CHIB) Office at DHMC offered a new series of free public lectures at the medical center on the challenging topics of substance abuse to teens and parents.

To kick off the series in March, Dr. James Sargent led a discussion about the influence media on teen substance abuse. At the April session, attendees viewing “Here Today,” a documentary film about heroin addiction, had the opportunity to interact with recovering addicts and family members featured in the film. In May, Robert

Bryant, program director for Second Growth, led a workshop focused on how to help a friend or family member with a substance abuse problem.

### Opening a Dialogue

The main goal of the series was to open up communication lines between teens and their parents. “We wanted to make it informative without being preachy,” explains Sarah Salo, CHaD events coordinator.

According to Carr Robertson, director of CHIB, the series was as informative for organizers as it was for attendees. “We learned that there is intense interest in these topics



and a real need to have these kinds of discussions,” she says. “We also learned how difficult it can be to attract multi-generational audiences. We’d like to offer more sessions in a less formal setting.”

# Helping Kids to

**T**HE CHILD LIFE PROGRAM AT CHaD—designed to provide opportunities for developmental stimulation, support during stressful procedures, and advocacy for children’s emotional and psychological needs—is busier than ever.

“We’re starting to expand our volunteer program so that we can support a growing list of activities that we would like to offer in the coming months,” says Jessica LaPerle, child life specialist and interim coordinator for the child life team at CHaD.

## Bringing Summer Camp to Kids

Camp CHaD, a program that offers play breaks for children staying in the hospital, has been so popular Child Life has expanded its original summer schedule to run year-round.

“We offer twice a day activities during the week,” says LaPerle. “I look at the schedule in morning and think about the ages and the developmental level of the kids and decide what play options will work best.”

When kids are having a difficult time with their hospitalization, LaPerle may pull together some emotionally expressive types of activities. “We might choose building projects that require hammering or make masks of different kinds of monsters to help give them words for their emotions,” she explains.

Just as often, activities are more directly focused on having fun. “We might have them make homemade silly putty or have a watermelon seed-spitting contest,” LaPerle says. “Kids in the hospital tend to feel isolated and it’s easy for them to become withdrawn, especially if they’re suffering from a chronic illness. This gets them up and moving around and really helps to normalize their day.”

## Dartmouth Athletes Come to Visit

One group of visitors that clearly enjoys participating in Camp CHaD activities is Dartmouth College athletes. “They get just as silly as the kids do,” LaPerle says. “It often extends our activity times, since the kids get more excited and involved.”

Several years ago, the men’s hockey team began making an annual visit to CHaD around the holidays, establishing the concept of “Team CHaD.”

This year, the program was expanded to include more teams. “We’re now visited by athletes from women’s hockey, football, women’s crew, field hockey, and men’s basketball at different times of the year,” she says.

In addition to participating in Camp CHaD activities, the athletes make bedside visits and play Nintendo and board games with patients. “It’s wonderful to see them interact and really get into being with the kids,” says LaPerle. “We’re hoping to have them participate in CHaD events such as our health and safety fair and the ski and ride challenge, as well.”

## Pet Therapy

According to LaPerle, Child Life recently increased its Pet Therapy Program visits to two per week. “The program has been running for about five years and it always gets huge patient and staff satisfaction,” she says.

Coordinated through the Green Mountain Humane Society, the program’s handlers and specially-trained dogs—including standard poodles, terriers, golden retrievers, yellow labs, and boxers—make hospital visits to provide comfort and companionship to patients. “We get approval from the physician, the parents, and the child before any visits are made,” LaPerle explains. “It’s amazing how much the kids look forward to seeing the dogs.”

The Pet Therapy Program is also offered to adult patients in the medical center. “One thing that they do on 1 East that we would like to incorporate as well is calling cards,” she says. “They include little biographies on each dog—we’d like to do them for the kids, perhaps as bookmarks.”

## Painting Their Troubles Away

Another therapeutic activity that LaPerle has been helping to coordinate recently involves reconstruction efforts in the Cancer Center. “They’re in the process of redoing a playroom and teen lounge area for cancer patients and their families,” she says.

“The nurses gave up their work stations to make more space available, so the construction crew could set up temporary walls for the kids to paint on,” explains LaPerle. “Oncology patients spend so much time in the clinic—it’s been a great release for them.”



# Feel Like Kids



# Providing Care

## *Continuous Pediatric Cardiac Care:*

### *Dartmouth-Hitchcock Manchester*

**H**AVING A HEART CONDITION can be a scary experience when you are an adult, but for children and their parents it can be a strange and difficult ordeal for the entire family. CHaD brings together pediatric cardiologists to provide first-class pediatric care locally at the Dartmouth-Hitchcock Manchester location. As the state's only children's hospital, the extension of CHaD in Manchester allows many of our specialists to practice care in the outpatient setting where children can benefit from CHaD's services and expertise locally and still have access to some of the leading pediatric experts.

The Pediatric Cardiology section of CHaD at Dartmouth-

Hitchcock Manchester has continued to grow over the years to meet the needs of children with heart defects in Southern New Hampshire. Additionally, CHaD's Regional Program in

**"Although it starts with clinical care, our staff goes beyond to provide emotional and financial support to our patients and families."**

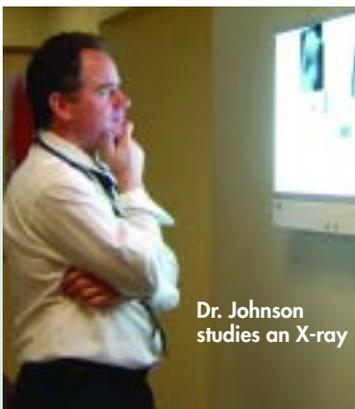
Pediatric Cardiology provides care not only at Dartmouth-Hitchcock Manchester, but also at several outreach sites throughout the state. For various treatment options, we also maintain a close association with the cardiology and cardiovascular surgery program at Children's Hospital, Boston.

The full-time Pediatric Cardiologists based in Manchester include Dr. Sol Rockenmacher, Dr. Irene Sadr and the newest cardiologist, Dr. Thomas

Johnson. Additionally, Drs. Michael Flanagan, Norman Berman and Steve Weindling regularly travel from CHaD at Dartmouth-Hitchcock Medical Center in Lebanon to CHaD

in Manchester to see patients within the department. Assisted by a full-time nursing staff, three technicians and additional medical support staff, the providers offer complete cardiac care for children as well as the necessary support services for their patients and families.

Clinical services in Manchester consist of cardiac diagnostic modalities including routine electrocardiography, plus Holter and long-term ambulatory monitoring, transthoracic



Dr. Johnson studies an X-ray

### **Announcing our newest pediatric cardiologist, Dr. Tom Johnson**

Pediatric Cardiologist Dr. Thomas Johnson joined the Manchester division of the Children's Hospital at Dartmouth (CHaD) this past September.

After more than eight years as a Pediatric Cardiologist in the Las Vegas, Nevada area, and most recently the Center for Pediatric Cardiology and Congenital Heart Disease, Dr. Johnson is happy to be in New England.

A native of Baltimore, Dr. Johnson received his medical degree from the University of Maryland School of Medicine. After completing his combined residency in Pediatrics and Internal Medicine from Albert Einstein Medical Center in Philadelphia, Dr. Johnson went on to the Medical University of South Carolina, where he completed his fellowship in Pediatric Cardiology. He is Board Certified in Internal Medicine, Pediatrics and Pediatric Cardiology (subspecialty).

Dr. Johnson's special clinical interest is in adult congenital heart disease. According to Dr. Johnson, "Thanks to many medical advances, the outlook for children with birth defects of the heart is better than ever before. Heart problems that were virtually untreatable just a decade or two ago, can now be treated successfully. However, patients with congenital heart disease can have persistent medical problems that are unique. One of my goals is to make sure that every patient continues to enjoy a long, healthy, and satisfying life."

and transesophageal, and fetal echocardiography. According to Dr. Irene Sadr, "With the expansion of our fetal cardiology services, we are able to assist the obstetricians with prenatal management, counsel the families appropriately, and help them prospectively plan the appropriate timing and location of their delivery." Additionally, pediatric cardiology services available at Dartmouth-Hitchcock Medical Center in Lebanon include cardiac catheterizations and electrophysiology testing.

Along with the outstanding clinical services provided, one of the most appreciated services is the understanding and sup-

# Locally

Dr. Sol Rockenmacher and Elaine Taylor, RN, team up in caring for patient Autumn Farrow.



port given by the entire department to the child and his whole family. “I like to think of our department as a unique cardiac medical home,” says Dr. Sol Rockenmacher. “We look at the full picture of the ‘family’ unit and help them deal with the stress of having a child with a cardiac problem. Through continual open communication, we try to make the process of working with larger medical institutions, such as Children’s Hospital, easier to manage and as seamless as possible.”

Elaine Taylor, LPN, a member of the Pediatric Cardiac nursing staff, adds, “Although it starts with clinical care, our staff goes beyond to provide emotional

and financial support to our patients and families, including support groups for siblings and caregivers. We provide continuous pediatric cardiac care.”

In addition to full-time services at Dartmouth-Hitchcock Manchester, Dr. Rockenmacher sees patients four times a month at Wentworth-Douglas Hospital in Dover and Dr. Sadr sees patients the first Thursday afternoon of every month at Southern New Hampshire Medical Center (SNHMC) in Nashua.

For more information on pediatric cardiology, call CHaD at Dartmouth-Hitchcock Manchester at (603) 695-2745 or visit their website at [www.dartmouth-hitchcock.org](http://www.dartmouth-hitchcock.org).

## Doll Donations Lift Spirit of Patients in the PICU

**T**HANKS TO THE GENEROSITY OF A LOCAL GRANDMOTHER, little girls who are being cared for in CHaD’s pediatric intensive care unit (PICU) can be the recipient of a delightful surprise—a beautiful, handcrafted doll.

“The doll-maker wishes to remain anonymous, so I can’t reveal her name,” says Elizabeth Stanton, a lawyer in the DHMC Risk Management Department who acts as the conduit between the woman and pediatric intensivists at CHaD. “We refer to her as the ‘fairy grandmother’—she truly is an angel.”

According to Stanton, more than a dozen of the dolls have been given to patients over the last couple of years. “She sends a new doll in every month for us, and I keep it until the PICU contacts me,” says Stanton. “Since they’re only reserved for patients who are at an appropriate age and have had a particularly difficult time with their hospitalization, receiving one a month usually satisfies the demand.”

Still, if she needs more dolls, Stanton knows all she has to do is pick up the phone. “If I called her tomorrow and told her we have five patients who could really use one, five new and amazing dolls would be delivered the next day,” she says. “Her generosity and love for children is inspiring.”



**Medicine  
Learning  
Discovery  
Hope**

**Call us today to learn how gift planning can support the future of children's care at CHaD.**

**Fred Moore, Director, Office of Gift Planning**  
**Phone toll free: 1-866-272-1955**  
**E-mail: [Gift.Planning@Hitchcock.org](mailto:Gift.Planning@Hitchcock.org)**

# New Heart Procedure Offers Hope to Parents & Children

**M**ANY OF US HAVE FELT A fluttering in our chest or have noticed that our heart has skipped a beat on occasion. While these instances can be anxiety provoking, especially for children, they are not usually considered harmful or dangerous.

Some forms of arrhythmias, however, present far more serious symptoms. “Impulses can sometimes occur outside the heart’s natural electrical pathway, causing abnormal and rapid activity,” explains Dr. Steven Weindling, a pediatric electrophysiologist at CHaD. Such is the case with supraventricular tachycardia (SVT)—a disorder that causes the heart to race 150 to 250 beats per minute.

## New, Safer Procedure

At CHaD, a new procedure called cryoablation is providing safer, more effective treatment for heart rhythm problems like SVT. With cryoablation, cold nitrous oxide is pumped through a catheter to ablate or destroy the abnormal heart tissue that is causing the arrhythmia.

The new technique offers several advantages over the traditional method of catheter ablation which utilizes radio frequency (RF) energy or heat to kill the tissue.

“One major advantage of cryo is it allows us to work very close to the atrio-ventricular (AV) node—a group of specialized cells that control the flow of electrical impulses between the upper

and lower chambers—without damaging the heart’s normal conduction system,” says Weindling.

## Avoiding Pacemakers

With cryoablation, the tissue in question is cooled enough to inhibit its electrical capabilities. “This allows us to map the area to see if we’re in the right spot,” says Wein-

**“We’re very excited to be able to offer this new and effective treatment option.”**

dling. “Once we are, we can cool the tissue further to destroy it.”

Another advantage of cryo is that the catheter actually sticks to the tissue that the physician is working on. “With RF, the catheter can sometimes move, resulting in heart block or permanent damage to the AV node,” he explains. “Once this happens, the patient requires a pacemaker.”

This is an especially troubling outcome for a pediatric patient. “I’ve seen it occur in other hospitals, and it’s tragic when a six year old needs to have one implanted,” he says. “Pacemakers have to be changed every seven to ten years, and require monitoring between surgeries. In addition to being invasive, they place significant limitations on a child’s activities.”



In the more than 1,500 cryoablation procedures performed so far on both pediatric and adult patients nationally, none have resulted in pacemakers, says Weindling. “That safety record makes everybody feel more comfortable,” he says.

## Higher Success Rates

Weindling believes the new technique will lead to higher success rates in the future. “We know

that with RF, there’s about a two to 10 percent recurrence rate after what you think is a successful procedure, and for some types of tachycardia that risk may even be a little higher,” he says.

With cryoablation, physicians can be more aggressive in their approach. “Now, with our ability to watch for transient heart block and reverse it with cryo, we can put extra applications down to get rid of the tachycardia



# CACs Join Forces to Fight Child Abuse

**A**N ANNUAL, JOINT effort between two Children's Advocacy Centers (CACs) was recently initiated to fight child abuse in the Upper Valley. The new collaboration, named "Shield our Children from Harm," involves CACs operated by The Family Place, which covers parts of Windsor and Orange Counties in Vermont, and CHaD, which serves Sullivan and Grafton Counties in New Hampshire. CACs are multidisciplinary teams that provide a coordinated response to victims of child maltreatment and their families—there are currently 332 CACs in the United States.

The partnership is a natural extension of the common interest and relationship the two organizations share as providers in the region, says Elaine Guenet, executive director of The Family Place. "It's important for people to understand that we're not duplicating services in this effort," she says. "Rather, our goal is to assure that all kids in the Upper Valley will have access to the same child-focused services when abuse occurs."

Representatives from the two organizations began meeting formally about a year ago. "CHaD was interested in attaining full designation from the National Children's Alliance, a process we had gone through a couple of years before," explains Guenet. "We also wanted to explore ways that we might work together. After a few meetings, we identified three areas to focus on—community education, professional development, and joint fundraising."

## A Community Call to Action

In April, the coalition hosted a half-day professional conference, dinner, and community fo-



**CHaD staff. Back row: Dr. John Modlin; Deborah Pullin, ARNP; Dr. Robert Reece. Front row: VT division director, Don Mandelkorn; NH Commissioner, Nancy Rollins; and Family Place leaders Linda James and Elaine Guenet.**

rum to help inform and educate the public about the incidence of child abuse, and to explore ways abuse can be prevented. Debbie Eappen, the mother of a victim of shaken baby syndrome, and Dr. Robert Reece, nationally known child abuse expert and medical consultant of the Child Advocacy and Protection Program at CHaD, were the featured speakers at the evening forum.

"Last year, there were 896,000 reported cases of child abuse in our country," says Reece. "That's three children a day, and those are only the ones we know about. This is a problem that is far-reaching and has an impact on every member of society."

According to Guenet, the community forum enjoyed strong attendance and is the first step in a multi-year effort to combat abuse. "By working together in a more focused way, we hope to raise awareness about the long-term societal costs and consequences of child maltreatment," she says. "As adults, we are the ones who carry the responsibility of keeping our kids safe."

substrate and at the same time make sure the AV node is working correctly," Weindling explains.

This offers hope for parents who have been searching for new treatment options for their child. "We've got a number of patients now scheduled for cryo whose parents wouldn't consider RF and also don't want their child to have to be on medication for the rest of their life," he says. "We're very excited to be able to offer this new and effective treatment option."

**I**N 2001, THERE WERE 903,000 substantiated victims of maltreatment in the US, or 12.4 per 1,000 children. As frightening as these statistics are, experts believe they do not reflect the true magnitude of the problem.

As harmful as each incidence of child abuse is, the effects don't end when the abuse stops. Victims often experience intense fear and shame, and must live with the emotional pain resulting from their abuse.

### Changing a Flawed System

Too often in the past, the system's responses to child maltreatment have been fragmented or have had the effect of further traumatizing children. "Professionals from the child protection, law enforcement, legal, and medical systems interviewed children separately and repeatedly in adult environments like police stations and emergency rooms,"

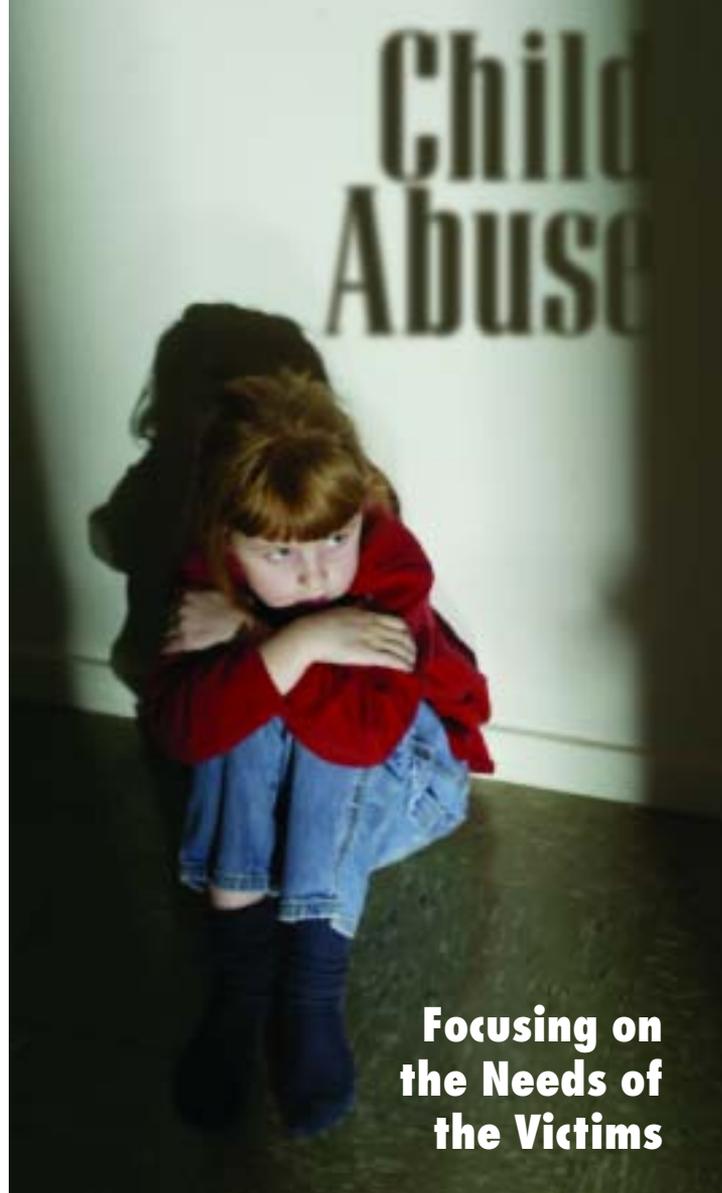
explains Elise Bon-Rudin, a child and family psychotherapist at DHMC.

These interviews focused on meeting the different requirements of each agency, which sometimes conflicted with one another. "The process was stressful for children and their families, and it created inconsistencies that made prosecuting cases more difficult," she says.

In the mid-1980s, Congressman Bud Cramer of Alabama led efforts to develop a more coordinated approach in the investigation, prosecution, and treatment of child abuse. Cramer formed the concept of the Children's Advocacy Center (CAC) which has evolved into a national model stressing agency collaboration and a child-focused approach.

### Creating a CAC

At DHMC, efforts are underway to create a CAC that will build on the success of the medical center's well-established Child Ad-



### Focusing on the Needs of the Victims

vocacy and Protection Program (CAPP). CAPP provides 24-hour consultation for CHaD cases in which concern about abuse has been voiced by the healthcare providers.

At the core of the CAC is its multidisciplinary team comprised of experts from law enforcement, child protection services, medical, prosecution, mental health, victim advocacy, crisis counseling, and other child and family professionals.

Working together, team members are able to gain a more complete understanding of case issues, track cases more successfully through to completion, and form a more consistent and supportive response for victims and their families.

### One Good Interview

The cornerstone of the CAC is the coordinated interview process. "A central goal is to ease the difficulty of the forensic interview for the child by providing a safe, child-friendly space that includes comfortable

furniture and toys," says Bon-Rudin, who is trained in forensic interviewing.

The child is met and interviewed by a professional who is specially trained in child forensic interviewing. A related goal is to obtain a complete and accurate report from the child, by using current knowledge about children's development and considering all reasonable explanations.

This allows interviews—which are videotaped—to be conducted in a legally sound, neutral, and fact-finding manner. "As the interviewer asks the child questions, other members of our team can observe through a two-way mirror and communicate with the interviewer using an ear piece," Bon-Rudin explains.

### Unique Resources Available

Another essential component of the CAC will be its medical evaluation area which the medical center is ideally suited

to provide. "The CACs that are admired most are the ones where there is a unified site for medical evaluations and forensic interviews," says Dr. Patricia Glowka, medical examiner for CAPP.

Some additional resources—such as CHaD's child life specialists and the Painfree Program for children—not typically found in other CACs, are available at DHMC. "We're also fortunate to have as our medical consultant Dr. Robert Reece, an international expert in this field," says Deb Pullin, pediatric nurse practitioner and CAPP coordinator.

"In the past, children would often be required to have multiple medical exams to assess for abuse," Pullin adds. "We really have a team approach here. Because we have several providers who do physical exams, in addition to our multidisciplinary team, we can make sure that all are in agreement about the findings and the plan to assist the family and child."

## Dr. Alexandra Elliott Brings Unique Expertise to CHaD

**I**F YOU ASK DR. Alexandra Elliott what she likes most about her chosen line of work, she'll give you a two-word answer. "The kids," she says with a smile. "I love helping them overcome their vision



succeed in school and their other activities."

As CHaD's pediatric ophthalmologist, Elliott specializes in treating a variety of eye problems in children, such as strabismus or crossing of the eyes. "The visual system in younger children is more plastic, so we have a window of opportunity

to correct problems before lasting damage occurs," she explains.

Catching problems early also allows Elliott to try less invasive methods of treatment. "I tend to be conservative in my approach," she says. "Patch therapy and glasses are often effective forms of treatment for visual problems. And these days, wearing glasses doesn't carry the stigma it did a few years ago—we can thank Harry Potter for that!"

### Providing Dual Specialties

Since coming to Lebanon last

August, Elliott has been filling a dual specialist role at CHaD. After completing a fellowship in pediatric ophthalmology at Boston Children's Hospital, she went on to complete extensive post-residency training in a unique sub-specialty called oculo-plastics at Emory Hospital in Atlanta.

"Oculo-plastics involves plastic and reconstructive surgery of the eyelids and eyebrows, orbit, and tear ducts," she explains. "Problems can be caused by a congenital disorder or trauma. Some of the most devastating injuries I've seen have come from kids playing paintball, an activity that I warn parents about all the time."

Dr. Elliott recently returned

from a two-week mission in Zambia, organized by an international plastic surgery group that sends specialists to train physicians practicing in developing nations. "My first mission a few years ago was to Morocco, during my first year of residency at Columbia Presbyterian in New York," she says. "I went with an oculo-plastics attending physician and assisted him with cases—that really sparked my interest in pediatrics."

"Zambia only has one plastic surgeon and five ophthalmologists in their entire country," Elliott adds. "It was great to be able to show them new techniques and to help them develop their capabilities to care for patients."

## CHaD Welcomes Back Dr. Paul Merguerian

**A**FTER A 10-YEAR HIATUS, pediatric urologist Dr. Paul Merguerian is returning to CHaD. "We're very excited about coming back to New England," says Merguerian. "My wife and I have always considered this to be our home."

In July, Merguerian will be leaving his four-year post as associate professor of urology and pediatrics at UCSF (Fresno), medical director of pediatric urology and chairman of the department of surgery at Children's Hospital Central California in Madera, CA, to move with his wife and two children back to the Hanover area.

Effective August 1, he will join CHaD's pediatric surgical services division, where his areas of specialty will include treating a full array of pediatric ur-

ological disorders. Merguerian's clinical practice will extend to Dartmouth-Hitchcock Manchester, where he will see patients two days a week. The Manchester site will also have a full-time nurse practitioner available to see patients.

### Treating Urological Disorders

Much of Merguerian's clinical work in recent years has been focused on treating pediatric patients whose urinary tracts and bladders are not functional because of different urological disorders.

"My main area of interest is reconstructive urology," he says. "For example, we use intestinal tissue to reconstruct the diseased bladder. Increasingly, these types of procedures are done laparo-

scopically, which is much less invasive for the patient."

Many surgeries to reconstruct the kidneys are also performed laparoscopically. "When a child is born with a urethra that is not completely formed, we can use local tissue to reconstruct the urethra with excellent results," he explains.

### Evaluating Problems Before Birth

Dr. Merguerian's expertise extends to pre-natal urology. "By utilizing ultrasound and other technologies, we can effectively diagnose and evaluate urological abnormalities before the child is born and work with parents



early on to determine what the best treatment options will be," he explains.

Urinary tract abnormalities that are detected before birth are more common than people would think. "The good news is most turn out to be benign and don't require surgery," he says. Much of Merguerian's research efforts will be focused on finding better tissue substitutes for reconstructive surgery.

"It's exciting to think about how we'll be applying the scientific discoveries we'll make in the next few years to better treat children with these disorders," Merguerian says. "I'm looking forward to returning to CHaD to do just that."

# Fun & Activit

## Ski Challenge: Upper Valley Community Spirit

A blue CHaDasaurus on skis? Children with green hair? Skiing with swimming pool noodles? Out of the ordinary yes, but not at the 5th Annual CHaD Ski and Ride Challenge! With a focus on good old fashioned fun, this year's CHaD Ski and Ride Challenge was anything but ordinary. Thanks to the hard work of a dedicated

group of volunteers led by **Tiger and Kristin Shaw**, the event raised over \$70,000 for CHaD. Proceeds are earmarked for the completion of the new CHaD Outpatient Center and continued support of CHaD's Injury Prevention Center.

Highlights of this year's event included a new nordic component kicked off by 4x Nordic Olympian

**Nina Kempell**, a new team challenge obstacle course relay competition, and a visit from the CHaDasaurus.

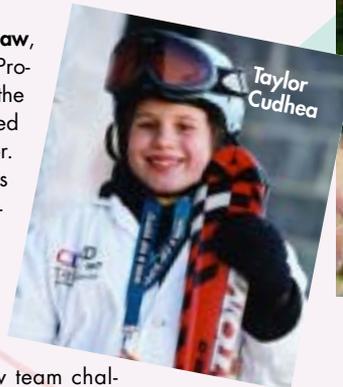
None of this would be possible without the support of many throughout the Upper Valley community. Many local businesses sponsor teams and provide in kind donations. Individual participation is also key. This year, eight-year-old **Taylor Cudhea** single handedly raised over \$3000, giving merit to the statement "Kids raising money for kids."

A special thanks to event sponsors: **Vox Radio, Tecnica, Volkl, American Express, Henderson's Ski, Golf and Ski Warehouse, Miller Auto, GDT, Omer and Bob's, Estes & Gallup, TK Sportswear, Alpina, Evergreen Capital Partners, Bagel Basement, and Murphy's on the Green**, who provided the delicious eats for the event.

A blue CHaDasaurus on skis? Anything is possible at the CHaD Ski and Ride Challenge.



Dressing up is just part of the fun at the CHaD Ski and Ride Challenge. (Left to right Erin Perryman, Carly Knights, Mikaela Shiffrin, and Maddie Dewhirst)



Taylor Cudhea

## The Bear Man is Back



**Jack Lessard**, also known as Jack the Bear Man to all his friends at the Children's Hospital, made his annual Christmas visit to CHaD with a truckload of stuffed animals.

Each year Jack delivers not only the stuffed animals, but lots of joy and smiles to the children in the CHaD Inpatient Unit. We're not sure who enjoys the toy delivery more, Jack or the kids.



## TOUR DE ROCKS

The **Northeast Willys Jeeps Organization** held their Annual Tour De Rocks on October 11, 2003. Gears, Guts, and Glory were definitely needed as they ground and winched their knobby tired vehicles over one of the most difficult bolder strewn trails in New Hampshire. All funds raised at the event were donated to CHaD.

# ies at WISHING WELL FOR KIDS XLS



XL92 DJ staff, CHaD staff, and a super volunteer get tangled during the last moments of the Radio-Thon.

As the finale to our month-long **XL92 Wishing Well for Kids** campaign, the radiothon was scheduled to run for three days. At the end of day three, we hadn't quite met our goal. The XL92 staff and our host, the Powerhouse Mall, didn't want to quit when we were so close, so they offered to continue for one more day. Day four was magic! The phones went wild and final auction bids became quite frenzied, and we ended the campaign with a record-breaking \$54,000! Once again, our community came together for the kids at CHaD to make this event an incredible success. From the kids who donated their allowance to our corporate donors every dollar truly counted! We also had an incredible corps of volunteers manning the phones for four days. Special thanks to Well locations, the **Power House Mall** and **Quechee Gorge Village**.



Key supporting businesses: **Mascoma Savings Bank, Pizza Hut, Christmas Trees of Vermont, Allen Pools & Spas, McLaughry Associates, McCarthy Construction, Fleet Bank, Ledyard Bank, Dunkin Donuts, Evans Fuel Marts, and Carpet Mill.** A huge thank you to everyone who participated and supported this wonderful event!



## SoBe Family Fun Day— Pepsi Supports the Kids

Perfect weather, games, super spring skiing, and great raffles made the **SoBe Family Fun Day** at Gunstock Mountain a blast on Saturday, March 13. Kids raced, played ball and stick winding games and more, all in support of CHaD. The SoBe Day was the brain child of **Amy Slide, Frank Tansey, and Dan Laura** of the **Pepsi Bottling Group**. This fun event is just one small part of a huge year-long Pepsi campaign in conjunction with the Wal-Mart stores of New Hampshire and Vermont in support of CHaD. The fun continues this summer with the raffle of a Gibson guitar signed by all the performers at this year's Meadow Brook concert series.

## Fuel the Care

Irving Oil's "Fuel the Care" program has come to the aid of NH and VT families in need. Irving provided CHaD with \$40,000 in fuel vouchers to help distant families get to their child's appointments. No longer do families have to choose between gas to get to a doctor's appointment and food on the table. The vouchers are for any family with a child receiving care at CHaD and living a distance of 50 miles or more. Irving Oil again has show itself to be a true CHaD Champion.



Irving Oil Representatives, Michelle Firmbach and Lou Beam (left) join with CHaD staff and families after the Fuel the Care press conference.

## Bravery and Generosity at its Best

Elaine Frank from CHaD's Injury Prevention Center receives a check from Firefighter **Bob Jordan** of the **Lebanon Fire Department**. Jordan was awarded a medal for bravery in saving the life of a child in a Lebanon fire last year. He donated his reward check to CHaD, a selfless act in true keeping with his brave efforts as a fireman.

## Sam's Club & Wal-Mart Rally Round CHaD



Wal-Mart Regional Manager **Paul Busby** and CHaD cystic fibrosis patient **Meghan Richardson** cheer on the crowd at the **Sam's Club/Wal-Mart** end-of-year rally held at CHaD last November. Store and District Managers, Community Coordinators, Associates, and Vendor representatives from **Pepsi, Coke, Keebler/Nabisco, Interstate Brands**, from all over New Hampshire and Vermont gathered to celebrate their \$250,000 achievement in support of CHaD, and to set an even larger goal for next year. **THANKS!**



**Circus Smirkus**  
is coming to town!!!

All Proceeds to Benefit

**Pediatric Oncology**

Order your tickets today before they sell out.

**Dartmouth-Hitchcock Manchester**

Saturday, July 10 at 2PM & 7PM  
Sunday, July 11 at 11AM & 4PM

**Lebanon Elks Club**

Friday, August 13 at 7PM  
Saturday, August 14 at 2PM & 7PM  
Sunday, August 15 at 2PM & 7PM

For information or to order tickets, call (603)650-3431 or online at [www.fnccc.org](http://www.fnccc.org)

CHaD Matters is published by the Children's Hospital at Dartmouth. Please address correspondence to: Sharon Brown, CHaD, Dartmouth-Hitchcock Medical Ctr., One Medical Center Dr., Lebanon, NH 03756.

Cover photo: CHaD patient Cameron Ramsey with a cuddly Wheaton Terrier Cross, Scruffy Wallach.

**SAFETY TIP DROWNING**

Playing in the water is one of the great joys of childhood, yet drowning is the second leading cause of unintentional injury-related death among children 14 and under. Each year nearly 400 children ages 14 and under drown while participating in water recreation and, in 2002, an estimated 2,700 children under 14 were treated in hospital emergency rooms for near-drowning and drownings. As many as 20 percent of near-drowning survivors suffer severe, permanent neurological disability.

CHaD supports the following water safety checklist that will be promoted by the National SAFE KIDS Campaign this year.

**SUPERVISE**

- Never leave a child alone in or near a swimming pool or an open body of water.
- Never allow young children to swim alone. Make sure older children always swim with a buddy and are supervised by an adult.

**TRAIN**

- Learn infant and child CPR.
- Teach children to swim after age 4.
- Knowing how to swim is not enough! Educate your children on all aspects of proper water safety, such as treading water and survival skills.

**EQUIP**

- Be sure your family always wears US Coast Guard approved life jackets when on boats, near open bodies of water, or when participating in water sports. Air-filled swimming aids, such as "water wings," are not safe substitutes.

- Keep rescue equipment, a telephone, and emergency phone numbers by your pool.

**PROTECT**

- Always apply a thick coat of sunscreen (SPF 15 or higher) before going out into the sun. Reapply sunscreen at least every 2 hours and after swimming. Check last year's expiration date before using this year.
- Urge pool owners to install 4-sided isolation fencing, at least 5 feet high, that is equipped with self-closing and self-latching gates.
- Make sure that your children swim in designated swim areas only.

For more information, contact the Injury Prevention Center at 877-783-0432 or log onto the National SAFE KIDS Campaign web site at [www.safekids.org](http://www.safekids.org).

**Saturday, June 12:** The CHaD Classic weekend kicks off with the second annual "Rock for the Kids" sponsored by **Golf and Ski Warehouse**. The fun starts at 6PM with dinner and dancing to the Warehouse Band, along with silent and live auctions. The evening's events conclude with this year's grand raffle drawing for a \$5,000 travel voucher. Tickets are \$30 per person. For reservations, call the Quechee Club at (802)295-9536.

**Monday, June 14:** The 20th Annual **CHaD Classic Golf Tournament**, presented by **Q.L.L.A. Charities, Inc.**, will be held at the Quechee Club in Quechee, Vermont. Over the past 20 years, the CHaD Classic has raised over \$900,000 for the Children's Hospital. This year, it will support the new CHaD Outpatient Center. Individual registration is \$300; sponsorship opportunities available. Tournament details: 8:30AM registration, with 11:00AM shotgun start. Contact Sharin Luti at (802)295-9201 or [sharinluti@adelphia.net](mailto:sharinluti@adelphia.net) to register.

**CHaD Events Schedule**

**Friday, July 23: Racing To Victory** and the **Governor's Breakfast** to benefit CHaD/David's House. Join us at the New Hampshire International Speedway in Loudon, NH, and meet **Busch North Drivers** and other **Nextel Cup** notables who will be on hand to sign autographs. Tickets can be purchased for \$30 each through CHaD Community Relations Office. Contact Terri Eastman at (603)650-3435 for more information.

**Monday, August 30:** First Annual **Bonneville and Son Celebrity Golf Tournament for Kristen's Gift**. Join celebrities such as former Red Sox great **Rico Petrocelli** on the links to support Kristen's Gift held at the prestigious Manchester Country Club. Individual player spots and sponsorships available. For more information, contact Terri Eastman, CHaD Community Relations Office, (603)650-3435.



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