



The Coalition Against Pediatric Pain (TCAPP)

May 2013

Welcome to TCAPP!

*Aurora Richards-Stipnieks, DVM; Board Member
TCAPP*

The Coalition Against Pediatric Pain (TCAPP) is a 501(c)3 organization committed to supporting and uniting families affected by pediatric pain, advocating for children in pain by increasing awareness of their needs, educating others regarding the long-term consequences of pediatric pain, funding research dedicated to pediatric pain conditions, and providing resources for families and professionals.

We were founded by five moms of kids that were afflicted or born with pediatric pain conditions. For more information, to help us out, or submit for future newsletters, please visit us at www.tcapp.org or email aurora@tcapp.org

This May 2013 newsletter will have a section on:

- + Ehlers Danlos Syndrome (EDS): May is EDS Awareness month***
- + Caring for Your Complex Child with Chronic Pain***
- + Writing From Kids in Chronic Pain***
- + Fundraising/Thank You to Donors Section/Future & Current Events***

Ehlers Danlos Syndrome

Do These Symptoms Sound Like You?

We are born into our bodies and that is our norm, thus it is shocking when you realize your body is not acting the way it was meant to be. For many years, life seemed pretty normal. But, looking back, I was mentioning things to others and now realize they were very strange – like in high school having my palms of my hands turn black and blue after clapping at a dance and also asking which way to put my elbows while on the parallel bars in gymnastics. But, I lived my life as an active person, not realizing I was born with a rare condition called Ehlers Danlos Syndrome, which was causing my collagen to be deformed. Thus, my ligaments and tendons are like overstretched elastic bands. This in turn allows joints to get too loose and causes painful subluxations, meaning partial dislocations.

Many others with this condition are like me and don't get diagnosed properly due to its rareness. It took me fifty-two years before a doctor recognized the symptoms and suggested what she thought was the problem. I had been sent to her due to a repeat bladder prolapse just two years after having the surgery to correct the sudden problem. She sent me off to a geneticist to confirm her suspicion before she would operate on me. I was grateful that she finally helped to put the pieces of the puzzle together for me. However, I was shocked to learn that at this time, it is an incurable condition.



The Coalition Against Pediatric Pain (TCAPP)

May 2013

So, what is one's life with EDS like? You have to spend your life being cautious with your every move. For instance, due to our laxity, a simple hug can cause the ribs and spine to move and sublux. The incidents of the body shifting increase with age, so does the pain. Three things are very important to get evaluated with this condition. First of all, we are prone to having a tethered cord, meaning the cord could still be pulling down on the spine. If not corrected, this will potentially cause permanent kidney damage. The next thing to check for is instability of the neck. We need to wear neck collars in the car to be safe due to this and some will require stabilization of the neck to regain strength. The other thing you need to check for is Chiari I malformation, where the brain tissue protrudes into your spinal canal. This can be surgically corrected and would alleviate the headaches one has to endure with this condition. Also, many of us also deal with severe osteoporosis.

It is important to learn how to properly care for yourself with this condition. For instance, you should not lift more than five pounds or it would cause more pain in the body, straining the ligaments and tendons. The core needs to be strengthened since the muscles are responsible for not only their job, but are also on overload taking over the job of the ligaments and tendons. Many with this condition also tend to have issues with digestion, with numerous food reactions and issues with metabolizing drugs. Celiac disease is not uncommon for many of us

to face. A manual therapist is a wonderful person to turn to for help for they can safely get you subluxations corrected. Also, if things persist, find a surgeon that understands the condition and is willing to use cadaver tendons to secure your joints.

Life with EDS is a constant challenge. Please help the next person you meet. Someday we dream of not only a cure but finding an understanding network of doctors to help us out. It is a lonely journey if you don't reach out to others.

If you have any questions, feel free to contact me:

Ellen Lenox Smith
Ellen.smith2@gmail.com
401-474-0115

21 Years Too Long

By: Sara E. Strecker

About a year ago I came across the form my mother filled out to admit me to kindergarten. They had asked for a list of medical issues and my mom dutifully filled out every idiosyncrasy - easy bruising, clumsy, exercise intolerance, likes quiet play. I'm sure the admissions committee who read through this dismissed her as a paranoid first time mom. It would be another 16 years of dismissals before I had a



The Coalition Against Pediatric Pain (TCAPP)

May 2013

name for the symptoms that were so clearly outlined a decade and a half before.

I was 21 when I was diagnosed with Ehlers-Danlos Syndrome, a collagen disorder that caused the easy bruising, the clumsiness (now known as poor proprioception: a.k.a “I don’t know where my body is in space”), the exercise intolerance and my preference for quiet play were defined as well (it’s hard to run around when your joints aren’t stable, coupled with extreme fatigue). The diagnosis, in my last year of college, finally gave me a name for what had made me different from all the other “kids”. Two years later, I was diagnosed with POTS (Postural Orthostatic Tachycardia Syndrome), which is often concomitant with Ehlers-Danlos. Essentially, when I stand up, the blood pools in my feet. My brain and heart don’t appreciate the lack of blood-flow as this registers as shock from blood loss (even though the blood is still in my body, just in the wrong place) and I get a rapid heartbeat and I drop in blood pressure, which led to seizures for me.

As I researched these conditions, I learned more about the symptoms that had plagued me all my life but, in hindsight these symptoms had steered me in my ideal career path. I’m currently a PhD candidate studying skeletal biology. I hope to continue my research in the skeletal field, trying to determine the molecular mechanisms behind collagen disorders – it’s a lofty goal for any researcher, and maybe a little crazy for someone with my medical issues, but I

have faith that I will succeed, if only out of pure tenacity.

When I was young, long before my condition had a name, all I knew was that I hated gym class and recess. I knew I could never excel at sports. I used to climb up the slide and sit on top, watching everyone play kickball or run around the basketball court. When I tried to join in (or when I was forced to by well-meaning teachers) I dreaded everyone running forward to catch the kickball, provided I even managed to kick it and not trip over it and my own feet. It made me feel like I was a failure. I tried to join in with everyone else anyway, and in first grade I fractured my humerus, right by my shoulder. This was the first of many fractures and sprains. Of course not one of my classmates, including the teacher, believed me because there was no cast (notwithstanding that you can’t cast a shoulder). So I was seen as a hypochondriac right from the start and I didn’t help myself by trying even harder to fit in and subsequently fracturing my elbow and my wrist, tearing tendons in both arms and my knee, and winding up on crutches for six months after an ill-timed jump in double dutch. The only good thing about all these injuries was I got to sit out of the dreaded gym class.

At 13, I had my own orthopedist and a file that was at least three inches thick. Every part of me had been X-rayed at least once. It should have been a clue to him, due to the fact that I was constantly in his office, that there was



The Coalition Against Pediatric Pain (TCAPP)

May 2013

something else wrong with me, but like my pediatrician, he just assumed I was clumsy. One event, which I remember vividly, changed how I saw these injuries. I had been working on a theater production and banged my elbow into the end of the metal bars that we hung our backdrops from. I knew something had broken so I called my mother and she took me home. We had been to the ER so many times over the years that there was a system. Unless I was bleeding heavily or in significant distress, we ate something first then packed a bag with books/ games / snacks to keep us entertained and fed for the next 6+ hours. This ER visit was different. The doctor took one look at my long medical history and decided I was a child abuse case. He was convinced that my parents were harming me. They took me into a separate room, away from my parents and questioned me for hours – convinced that somehow my parents had hurt me. They refused to give me painkillers (even Ibuprofen) for the fracture until I “confessed” and even though I had a broken bone, the doctor was so angry with me due to my refusal to come out against my parents that he sent me home without setting the fracture. Unfortunately, my parents were questioned as well, and they were as confused as I was, since they weren’t even in the building when my injury occurred. Thankfully, it was decided that they weren’t abusing me, but I was scared. At that point, I refused to go to the hospital unless I was convinced something was broken. I started paying more attention to my own body and learned that the sharp pains I felt

after an injury could often be relieved by manipulating the joint until it popped. So began a long journey into understanding how my body worked and what I could do, instinctively, to lessen the pain. I now know that I was relocating various dislocations, but at 13 I had no name for the procedure or the condition – all I knew was that I was doing something that helped me live a more normal life.

I had learned a long time ago that I would never be a sports superstar. I didn’t have the stamina to compete with my classmates and my myriad of injuries made consistent practice all but impossible. I figured, since I can’t be good at sports, I can be good at school. I focused on my coursework, trying to get into the best college that I could. I was able to get A’s in my courses even while I was getting C’s or just being marked “excused” for g

It wasn’t until I got to college, and had the serendipity of being paired with a roommate who was also bendable, that I realized I wasn’t just klutzy or a hypochondriac, that there was something actually wrong with me. “Normal” people didn’t have to reset their hips and shoulders when they got out of bed in the morning. “Normal” people didn’t use their hips as whiskers because they weren’t aware of how wide the door was. “Normal” people weren’t on a first name basis with the campus health center staff. The campus health center staff was, essentially, useless but from them I got a recommendation to see a rheumatologist. Said



The Coalition Against Pediatric Pain (TCAPP)

May 2013

rheumatologist was also quite useless as he dislocated most of my joints then told me that he felt that all women were bendy and therefore nothing was wrong with me, but decided to send me to a geneticist anyway to make sure. It took a mere five minutes for the geneticist to diagnose Ehlers-Danlos. I thought my saga was over.

But I was still exhausted and had started having seizures on a regular basis. The geneticist, after her initial diagnosis, didn't feel the need to see me again, so I had no answers as to why I couldn't stand for long periods of time and would go into convulsions when over-stressed. I finally had a seizure in the living room of my apartment and my roommates called the EMTs. The EMTs were convinced I was a drug overdose, especially when I didn't have any palpable blood pressure. They carted me away to the hospital, believing their blood pressure cuff was broken and I'm sure were disappointed to learn that my drug screen was clean. Eventually, an astute neurology resident realized there was something wrong with my heart that was triggering these "seizure-like" episodes, but it took another two years for me to find a cardiologist who would order the correct tests to diagnose me with Postural Orthostatic Tachycardia Syndrome (POTS) and treat me.

I had been reading all I could on Ehlers-Danlos in the interim and had decided I needed a change of pace. College was basically engineering with a smattering of biology. So,

graduate school, specifically my Master's degree, became basically biology with a smattering of engineering. I've been interested in bone since I was little, perhaps because I was X-rayed so extensively at a young age. It wasn't until midway through my Master's degree that I was fully diagnosed, so I knew then I needed to help people who were still searching for their own answers. I couldn't go into medicine because I knew I wouldn't be able to physically handle the rigors, but medical research seemed like a pretty good fit.

The one thing that allowed me to be where I am now was the idea that I was not disabled, but differently "abled." Having spent so many years having to learn about my body and its eccentricities has made me incredibly adaptable. I know exactly how far I can push myself and how much I will suffer if I push too hard. I know my body better than any doctor and I have to take care of it so I can function well into the future, and hopefully do some good for those who are suffering in the endless cycles of wrong-diagnosis and accusations. I wish I had been diagnosed at age six, with my first fracture, but since that wasn't meant to be, I can at least tell the world about Ehlers-Danlos and make it a household name, not just for patients but for doctors. With research and education we can make lives better for those affected.

It shouldn't take 21 years (in my case) or 64 years (in the case of my father) to finally gain understanding for why our body works



The Coalition Against Pediatric Pain (TCAPP)

May 2013

differently. Sadly my story isn't all that different from most medical zebras. No one should have to suffer needlessly. Early identification, diagnosis and eventually, treatment, are my goals for the future. Together we are a force to be reckoned with and we can change the medical profession for the better!



Caring for Your Complex Child

Meeting the New Specialist: Creating Your Best Experience

Alisa L. Niksch, M.D.

The journey to find specialists who have expertise in treating challenging chronic diseases in children has most likely been a taxing and overwhelming effort. As a parent, you have probably felt angry, frustrated, sad, or even threatened during this process. Experiencing this level of stress is not surprising at all, given that many practitioners, school officials, friends and family may be mystified by the symptoms your child is experiencing. It is often by chance that you come upon the possible diagnosis of your child, and the majority of times it may not be from the medical community.

Once you have discovered a center where these relatively rare conditions are treated, there are high expectations for the first visits. Many diagnoses, such as a suspected connective tissue disorder, metabolic disease, or mitochondrial disorders may merit evaluation by a genetic specialist. However, due to schedule availability, you may see a different pediatric specialist as your initial visit. This may be a pediatric cardiologist, neurologist, orthopedic surgeon, rheumatologist, or even a rehabilitation medicine specialist. Despite this, progress can be made in the diagnosis and treatment of your

child's condition depending on what information you offer, and what evaluations are performed as a result. How a physician listens and responds to you and your child will be a major factor on whether you decide to continue care with them.

Physicians also can become overwhelmed quickly when they are confused, and what patients get out of a physician's visit is often dependent on how they present the problem. Families of children with especially complex disease should not expect every aspect of their disease to be fully addressed during the first round of visits. However, it is useful to select the most overwhelming complaints, and be able to describe the "5 W's" of the symptom: who, what, when, where, and why. Physicians also want to hear the child describe what they are going through as much as the parent's observations. In this age of technology, you may already have a photo or video of certain symptoms, or have vital sign information from a school nurse or emergency room encounter. Whatever information you have collected, it is extremely important, and even empowering, to have a file on your child's health. You will quickly become the victim of information overload! However, if each physician's recommendation is recorded clearly, it will keep things straight for you, and for other participants in your child's treatment plan.

The other information which is essential to share with your new caregivers is the contact



The Coalition Against Pediatric Pain (TCAPP)

May 2013

information to other important people and places in your child's life. This may include your primary pediatrician's office, pharmacy (including a local compounding center), school nurse, and physical and occupational therapists' office. There are often particular challenges which your child may be facing as a student, and we may need to provide information or make specific recommendations to modify his or her educational plan. We hope that this will minimize any conflicts with the school, ensure delivery of needed services, and improve the effectiveness of our therapies.

I wish all of you the greatest success in finding the right physicians for your child. While not every specialist may have the ultimate experience with complex pediatric diseases, if they are open and willing to learn along with your family, this may be the perfect fit.

The Role of PGx in Pediatric Pain Management

National agencies, including the FDA and **National Institutes of Health**, are encouraging more prescribers to consider pharmacogenomic (PGx) testing during normal practice. Pharmacogenetics is a term used to describe the affect genetics have on drug metabolism. This is significant because pharmaceutical companies design drugs for people who are deemed 'normal metabolizers' of drugs - yet over 75% of the population have detectable variations in

their DNA that create a higher risk of having an adverse drug reaction from toxicity - or the opposite - a lack of efficacy from medications they take.

Over one hundred drugs now include FDA guidelines for PGx testing on their labels, including popular analgesics such as hydrocodone, codeine and celecoxib, and many ADHD medications like Adderall and Strattera are also known to be impacted by pharmacogenetics. However, while most people can intuitively understand the benefits of PGx testing in adults, there is a growing need to expand this testing to the pediatric population.

Four cases of fatal opioid adverse events in children prompted the FDA to issue a Drug Safety Communication in August 2012¹. All four children received normal doses of the pain-killer codeine as part of normal post-operative procedure following nose and throat surgery, however, serious respiratory depression developed within a few days. Three of the children died from these complications.

Codeine, along with other common medications such as morphine or oxycodone, is part of the opioid family of drugs. Opioids are powerful pain killers, but can be very problematic as they are metabolized by the highly polymorphic CYP superfamily of enzymes. Codeine's specific pathway is CYP2D6, which along with the

¹

<http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm315497.htm>



The Coalition Against Pediatric Pain (TCAPP)

May 2013

enzymes CYP2C9 and CYP2C19, is at least partly responsible for metabolizing 40% of all common medications.

Genetic variations are both common and problematic. In the 2012 cases, all four children were found to possess the CYP2D6 ultra rapid metabolizer phenotype. These variations caused codeine to be processed into morphine too rapidly in the children's cells, resulting in dangerously high levels of active metabolites in the children's bloodstream. It's estimated that 7% of the general population possesses the ultra rapid metabolizer phenotype with percentages rising to as much as 29% in certain populations.

The FDA concluded their Drug Safety Communication by saying that they are currently investigating other possible cases of severe adverse drug reactions in children. They advised prescribers to be conservative with their regimen choices when working with children.

Prescribers are encouraged to educate themselves and their patients about the importance of pediatric pharmacogenomics. Childhood is a unique period of a patient's life. Many physiological and metabolic changes occur throughout development. Many life-long conditions also develop during childhood, including autism, Ehlers Danlos Syndrome, or juvenile diabetes. A better understanding of genetic variations within children could help improve pediatric care by ensuring these children receive medications that work best in their bodies without creating potential harm.

A recent study in the *Journal of Pediatric Pharmacology and Therapeutics*² says, "given the potential for genetic and age-dependent factors to influence drug selection and dosing, pediatric pharmacists should be involved in the development of dosing recommendations and inter-professional practice guidelines regarding pharmacogenomic testing in pediatric patients."

Prescribers are also encouraged to seek out and demand education opportunities regarding PGx. While many schools and institutions are beginning to offer pharmacogenomics as part of the normal coursework for pharmacists in training, there is still a need for more learning opportunities for prescribing physicians who are rarely exposed to pharmacogenetics in their education.

Genelex is a recognized leader in pharmacogenetic testing and personalized medication management software. The company's high-complexity laboratory has over 25 years of DNA testing experience and in 2000 became one of the first labs to provide PGx testing. Its YouScript Personalized Prescribing System tests the three most clinically-significant enzymes (2D6, 2C9, and 2C19) and provides clear, actionable guidance on probable effects, recommended management and safer alternatives to help practitioners eliminate adverse reactions. Each test is reviewed by a

²

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3208440/>



Because no child
should live in pain.

The Coalition Against Pediatric Pain (TCAPP)

May 2013

team of consulting pharmacists and includes access to the YouScript Personalized Prescribing software for detecting probable drug-gene and cumulative interactions at the point of care. For more information visit www.YouScript.com



The Coalition Against Pediatric Pain (TCAPP)

May 2013

In Their Own Words (Kids in Pain)

"The Challenge of Pain"

By Melanie Dickens

In my life I'm challenged by peer pressure, school, and stress, but the biggest challenge I face is here to stay. It's RSD, the monster inside of me. There are so many things to consider when dealing with this disease of pain. Is this going to be hard? Will I have regrets? Don't let the bullies bother you. Cope. Mask your pain and suffering. It's my biggest challenge, plus in years to come I wonder if I'll be safe alone. Will I be accommodated? How do I overcome the daily challenge of pain?

On January 24th, 2010, I experienced a simple injury, struck with unbelievable pain, and given a monstrous challenge to overcome nonstop pain. Each day I wake up to the challenge of my life as a game of spoons. In the morning I start with twenty spoons. School leaves me with just 10 spoons to get through my day. Add homework and subtract three or four spoons. Play with friends and there go a few more. Therapy is at least three spoons. By now I've used them all and it's only 5pm. I'm done! Wait! Rewind! I don't play with my friends outside, instead invite them to watch TV or use the computer so I can get through the day with crashing at 9 pm.

I balance activities (manage my spoons) but still face my pain. I have to find my mask. Grimace,

don't yell. Express pain through your eyes, not on your entire face. Smile, don't frown. Hide the limping. Act silly or perky to hide the despair inside. Act normal after the bullying, don't let them see the damage and hurt to your heart: the daily charades of my mask covering the hurt, despair, and the emptiness that only I can see. Only I can see the scrambled mess that is my heart and brain, and is hidden behind that mask.

What happens when I go off to college, when I'm on my own without my parents to back me up, with nobody who knows from the beginning? All over again with the skeptics and disbelievers, the horrid game of who is a real friend or who gets what is in my head. I live this life every day. It is a scary game of what I will face now and what I will face in my future. How do I overcome the challenge of pain?

The Things I Love About Pain--

by Alivia

1. Having to stay in instead of being able to go out and play.
2. I can't stand in one place for too long. I also can't sit for too long.
3. Missing going to school.
4. On bad pain days, I can be distracted from concentrating on things I have to do.
5. Lots of people, especially doctors, don't believe me.
6. The pain keeps me up at night.
7. I'm tired a lot.
8. I can't do a lot of the things I love to do.
9. I can't finish a lot of the things I start.
10. I miss out on trips to places – because they are inaccessible for me.

--NOT!!!



The Coalition Against Pediatric Pain (TCAPP)

May 2013

The Story of Fundraising and Support

By: Shan Nolan

Shelby Nolan is a 12 yr old from Minnesota who was diagnosed with RSD/CRPS in March of 2012. She has it in her left side of her body. Like most kids with RSD, she has had a tough time and had to endure things that most adults can only imagine. She has become a fighter and actually a tough little cookie. Even though she has lost a lot, she has developed an empathy that most adults do not have. Our children, though in pain, will survive better in this world than most.

Recently ten of Shelby's classmates and friends wanted to help. They made Orange RSD bracelets over the course of two weekends and asked their school if they could sell them before school and at lunch. The school principal was very supportive and allowed the girls to sell them. They charge \$4.00 per bracelet, and students from 5th-8th grade purchased them along with staff. The word got out and parents and other adults sent in money to support the cause. They also bought RSD T-shirts online and wore them during the sales. They created a little write-up about how Shelby feels and really did a nice job educating her school. They felt the need to do this, because some of the teachers and students did not understand RSD and were teasing and giving Shelby a hard time. With the help of the girls and the principal – this does not happen any longer.

I am impressed with the selfless act of the girls and hope that “someday” the rest of the world will understand this monster of a disease.

This is the Fact Sheet the Girls Made to Support Shelby:

- ✚ RSD stands for Reflex Sympathetic Dystrophy. It is also known as Complex Regional Pain Syndrome.
- ✚ RSD pain is rated as the most painful chronic disease that exists.
- ✚ Minor injuries, such as a sprain or fall can cause RSD/CRPS.
- ✚ Symptoms include persistent moderate-to-severe pain, swelling, abnormal skin color changes, skin temperature, sweating, limited range of movement, and movement disorders. RSD patients feel like they are burning from the inside out.
- ✚ RSD is 2 to 3 times more frequent in females than males.
- ✚ How Can I Help? Support those with RSD. They look normal on the outside, but are in pain on the inside! They may feel good one day and terrible the next day. Touching or wanting to hug someone with RSD can be painful! Use your words and express your support! Many kids with RSD have to give up their favorite activities and sports because of the risk of injury and pain. Imagine having to give up your favorite activity or sport!!!



The Coalition Against Pediatric Pain (TCAPP)

May 2013

Current & Future Events

"On-Line Auction at Bidding for Good"

Our fundraising coordinator Nina Train is working on TCAPP's first ever On-line Auction. We have already collected signed sports and music memorabilia, prime seats at a Yankee Baseball game, an American Girl Doll and more. The on-line auction will take place June 17th – July 17th through Bidding for Good and will be accessible nationwide and open to everyone!!! To help promote this on-line auction, get us some auction items, or, to just log in and bid, please contact aurora@tcapp.org or nina@tcapp.org for more information.

"Pediatric Pain Conference"

On Sunday, August 4th, 2013 TCAPP and the Warren Alpert Medical School of Brown University will host the first ever pediatric pain conference and think tank bringing together esteemed pediatric and adult medical experts from across the country to come together to learn, share ideas, and strategize how to better offer treatment. Dr. Chopra, head of TCAPP's Medical Advisory Board states "We need to educate each other from our different perspectives and training so we can find out what works and what doesn't, what we know and what we need to know." The meeting is approved for AMA PRA Category 1 Credit.

If you have a personal physician (any specialty) that you feel would benefit from this conference

and would like us to send them the information on how to sign-up, please contact either barbara@tcapp.org or aurora@tcapp.org.

For those that wish to have access to this information, please know that TCAPP will have the lectures available by video after the conference.

"It's Not All in Their Head"

How many of our kids were given an incorrect "lazy" diagnosis? What were they and how long did it take your child to get correctly diagnosed? Barbara Granoff, one of our board members, was told in the beginning by a pediatrician, that "it was all in her daughter's head" even though one foot was freezing and numb, and the other was normal. When she asked how a 10 year old could do that, he said "swamies in India could do it." She was also told by a neurologist after a 15 minute exam that it was Conversion Disorder and he asked what she and her husband had done to make her that way.

The Coalition Against Pediatric Pain is particularly concerned about this issue and is discussing ways to bring it to light, so we can better educate doctors and help families.

We are working with a pediatric psychiatrist on our medical advisory board to figure out a way to do this and are interested in your stories. If you are going to be at the EDNF conference in Providence, RI, (or live nearby) we'd love to meet in person. Or, if interested in other ways to get involved, please contact Barbara at Barbara@tcapp.org.



The Coalition Against Pediatric Pain (TCAPP)

May 2013

Donations (Thru April, 2013)

"In Memory of Dr. Allan Granoff"

(June 26, 1923-May 13, 2012)



Ms. Joan Levine
 Isabelle & Strom Thacker*
 Pradeep Chopra*
 Sherrie Giannoti
 David Kingsbury
 Susan & Charles Pinkham*
 Charles French Toney
 Keith E. Wilson
 Denise Champagne
 Stephen D. Moss
 Steven Lee
 Jim Broatch
 Aurora & Stephen Richards*
 Harold Rosenblum
 Paul Bender
 Joel Banes*
 Robert Webster
 Allan Portner
 R.W. Simpson*

"In Honor of Pradeep Chopra, M.D."



Nell Clamor
 Southern NE Anesthesia
 Jim Broatch
 Rebecca A Verity
 Susan & Charles Pinkham
 Monica & Michael David
 Edwin & Lisa Sutcliffe
 Michael Chatwin Senior
 Barbara Granoff
 Kenneth & Judith Denhemel
 Anthony & Sandra Conte
 Kathleen & William Garcia
 Stuart & Esther Schneiderman
 L.C. Czech
 Daniel Davey & Rita Vaughn
 Patients and Staff of Dr. Pradeep Chopra
 Lynne & Timothy Adams
 Robert Wells*

"In Honor of Karen Richards"

Aurora & Stephen Richards*
 Karen Van Der Water
 Kara Farrell
 Amy Read



The Coalition Against Pediatric Pain (TCAPP)

May 2013

Items Made, Sold, & Donated

TCAPP Cards Donated by The Haft and Hurwitz Family*

Designed By: Lexi Haft and Alison Hurwitz



Handmade Jewelry Made and Sold By:
Julia Rauch

Handmade Dollhouse Donated for Raffle
By: Carole Stepanek*



Special Events to Raise Money for TCAPP

Self Defense Class

Hosted & Donated By: Rolando Perez, Personal Best Karate in Medfield, MA*

Organized By: Sarah Waters



Yard Sale Proceeds:
Holly Ann Moriarty Pierce



The Coalition Against Pediatric Pain (TCAPP)

May 2013

Fantasy Sport Leagues Run By:
Stephen Richards*

Pinkham Advertising* -- Donated Time for
Brochure, Letterhead, Business Cards and Event
Flyer Designs

Worcester Sharks Game Fundraiser
Organized by: Sammie Barrett

Donations In Kind

Aurora & Stephen Richards*
Susan & Charles Pinkham*
Barbara Granoff & Mike Strongin*
Tawny Kasten*
Isabelle & Strom Thacker*
James & Cydney Broatch
Maris & Anita Stipnieks
Sheldon Golden
Karen M. & Dennis P. Curley*
Robin & Bennett Greenspan Fund
Maryann Carnavale
DCU For Kids*

Companies that Have Volunteered Their Enormous Time and Resources

Cyberfluent, Inc.* – Donated our Beautiful
Website: www.tcapp.org

Boston College Legal Assistance Bureau
(BCLAB)* – Donated their Legal Services to
Help TCAPP Become a Reality and Have
Donated Their Time to Serve as a Legal
Counsel

** Donates a Special Friend to TCAPP with an event or
monetary donation of \$250.00 or More*