

CSD NEWS

A publication from the staff of the
Center for Skeletal Dysplasias at Hospital for Special Surgery



It's our second anniversary !!! As of July 2005, the Center for Skeletal for Dysplasias is completing its second year. A lot has happened in the past 2 years; the last 6 months alone have been a whirlwind of exciting progress. So, to keep everyone informed, "in the loop", here's all the latest CSD news.



NEW FACES, NEW BEGINNINGS

Hopefully you all have received the notice that we have had staff changes at CSD. Our new Clinical Coordinator/Genetic Counselor, *Erin Carter*, started with CSD in May 2005. Erin is the kindly voice you will hear when you call CSD to make an appointment or have some CSD related need.

Kelly Sindle is the CSD Physical Therapist. Many of you may have met her during your initial CSD appointment. Kelly is available during Center appointments to suggest and demonstrate patient specific exercises as well as make suggestions for adaptive equipment.



CSD MENTORING PROGRAM

We are very excited to announce a new specialized program available to teen-agers who are CSD patients. Due to the support of the Hodgson Family, we are now able to offer a mentoring program for CSD patients to help them develop work skills that are

compatible with individual talents and abilities as well as to help with career planning. Internships are available at Hospital for Special Surgery for CSD patients ages 15 to 18 years old. 2 types of internships are available:

- Academic year—8 hours/week for 25 weeks.
- Summer—25 hours/week for 8 weeks

Travel expenses, up to \$ 100/month will be reimbursed and participant will receive a stipend of \$ 2000 upon successful completion of the internship. Mentoring program will also be available to help assist with application fees for college or specialized program/trade school. Assistance with exploration of funding sources for higher education is also incorporated into this unique CSD program.

So, for anyone interested, here is how to apply:

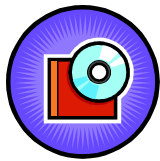
- The applicant must submit a letter to the CSD staff telling us why he or she would like to be a part of this program.
- Applicant must submit 2 letters of recommendation: one from staff of the school that the applicant attends and one from a personal contact.

Once an applicant is approved, we will meet with the student and family to discuss the specifics of the internship site and the program. Students may have more than one internship over time; however, once the student is 18 years old, he or she will no longer be eligible to participate in the program. (If the student turns 18 during the course of an internship, he or she will be able to continue with the current internship.)



BEING SOCIAL AT THE SOCIAL CLUB

On April 20, 2005, a very unique event occurred to benefit the continued efforts of CSD. An after work party at The Social Club in Manhattan offered the perfect balance of live entertainment, lovely people sponsoring CSD and cocktails. This fundraising endeavor, plus a raffle for a flat screen TV, sparked great interest and generous support to the Center. A very sincere and heartfelt thank you to the Burke and Cannon families for their tireless efforts and extraordinary dedication not only to CSD but to each other.



WE ARE ONLINE !!!!!

Ever have trouble answering questions about what CSD is or where Hospital for Special Surgery is? Here's a simple solution. Tell your family and friends to check us out online. Thanks to our friends at Hedley Media Inc., CSD has its own very personal DVD that lets everyone know who we are and what we do, while providing education about skeletal dysplasias.

Check out the HSS website to find out about CSD and view this distinctive DVD. It is located at www.hss.edu and CSD is listed under Departments and Services.



CALLING ALL ARTISTS & POETS

We know you are a creative bunch; so, let's put all that talent to good use. We are looking for *drawings* (no bigger than 8 1/2 x 11 inches), *poems*, *short stories* from all of you (children, adults, siblings, parents, partners) to use for several artistic endeavors. Our first project is going to be creating a 2006 calendar; therefore, we need your masterpieces by *August 31, 2005*. Feel free to send as many examples of your creativity as you want to us either in the mail or via e-mail. All submissions will become part of our CSD Gallery. Each month we will display the original works you have submitted during Center dates so that the HSS community can view your talent and creativity.



MAKING NEWS

At the LPA National Conference in Orlando, Lorraine Montuori was invited to lead her specially designed workshop, *What It's Like Being Me*, for children and siblings whose lives are impacted by skeletal dysplasias. Participation in the workshop sessions was lively and well attended.

An article, *A Matter of Size: The Sky Is The Limit For People With Dwarfism*, in the 1/9/05 edition of the Star-Ledger newspaper featured interviews with the Burke family, Dr. Raggio and Lorraine Montuori. (Reprinted on next page)

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A Matter Of Size

The Sky Is The Limit Today For People With Dwarfism

BY PEGGY O'CROWLEY
STAR-LEDGER STAFF

Ryan Thibault's face was set in determination, his dark eyes intent on the wrestler at the other end of the mat. At 4-foot-3, Thibault seemed to be at a decided disadvantage. But the 17-year-old has learned to adapt his wrestling style, using strengths like a lower base of power to offset potential pitfalls like getting caught in moves by his taller, longer-limbed opponents.

This night, in Thibault's first varsity match for Hanover Park Regional High School, the strategy worked. He pinned the Chatham High School wrestler in 39 seconds.

Thibault, 17, is a "person of short stature," or a dwarf, born with a condition called achondroplasia. But he has an enormous will, one that has enabled him to wrestle on the varsity team, manage the school's football team, hold down a job and drive his own car.

"I'm not one to give up. I like to succeed in life, and if I set my mind on something, I don't stop," he said.

For Thibault and other young people with dwarfism, the sky is the limit. It's a long way from the time when many families kept their children home for fear of teasing or bullying, and didn't encourage them to develop careers or a plan for life. Today these kids are going to college, playing sports, working and dating. New surgical procedures and treatments enable adults to live active, healthy lives. And a broad social network helps them to advocate for themselves and provide support to each other.

They have role models like Paul Steven Miller, a law professor at the University of Washington, the actor Peter Dinklage, who starred in the Jersey-based indie hit "The Station Agent," and Anthony Soares, a Hoboken councilman.

"Things are much different today. People are more educated about little people," said Helen Finkel, 42, of Manalapan, referring to the term many dwarfs use to describe themselves.

Finkel, president of the Garden State chapter of the Little People of America, remembers her father insisting she be enrolled in the kindergarten class of her local school. "The principal didn't want me in school because I was short.

He considered me to be disabled, mentally disabled," she said.

After graduating from college with an accounting degree 20 years ago, she found it difficult to get a job. When she arrived for an interview, "at first they'd be taken aback, then they would be cool and go through the motions, and I knew I wasn't going to get it."

While Finkel, an at-home mom, has a good life, she believes her daughter, Samantha, 8, who is also short-statured, will have an easier time. One reason is that she was prepared to raise a dwarf, since people with the condition have a 50 percent chance of giving birth to a little person.

But like most people of short stature, Finkel was born into an "average-size" family. The most common form of achondroplasia is due to a gene mutation or change during pregnancy. Most parents have no idea their child will have achondroplasia until after the birth, and it can be a shock.

"Achondroplasia occurs in one of 26,000 births, and it seems miniscule. But if you're the one, it's 100 percent," said Lorraine Montouri, a social worker for the Center for Skeletal Dysplasia at the Hospital for Special Surgery in New York.

Montouri counsels parents whose children are born with the condition, as well as adult little people.

"They are concerned about the way the child will be treated by the world," she said. While that concern is valid, Montouri said the adults she sees have had "a tougher emotional road. People in their 30s and 40s and up have gone through a much harder time. They've had social isolation, been placed in special ed classes or never learned how to be self-sustaining."

With a greater push for mainstreaming, younger little people are leading lives much like their average-sized friends.

Michele and John Burke were typical of first-time parents dealing with the condition. The ultrasound in Michele's 20th week of pregnancy was normal, she said. It was only after Emily, now 7, was born at Holy Name Hospital in Teaneck that an orthopedist was called in, she said. Two days later, Emily suffered a seizure and ended up at Columbia Presbyterian, where she was diagnosed with achondroplasia, she said.

Like many babies with the condition, Emily was suffering from a compression of the opening at the base of the brain affecting the brain stem and spinal cord, which can cause breathing to stop. Since a neurosurgical procedure to enlarge the opening, she has never had a seizure again. She has had her adenoids and tonsils out and tubes inserted into her ears to treat the infections that can occur because the nasal and ear passages are narrow.

And the family was told that Emily's developmental milestones, like sitting up and walking, would be delayed from six to 12 months.

"Nowadays we're lucky. When we see a baby, we tell parents, this is the way it's going to be. We give them a road map that says, "Here are the things we know in 2004," said Cathleen Raggio, a pediatric orthopedic surgeon and co-director of the Center for Skeletal Dysplasia.

Seeking support from the local Little People of America chapter was critical in helping the family cope, Michele Burke said. "We have met so many really nice people, LP adults who have happy families," said Burke, of Pearl River, N.Y. Now, she said, "seeing Emily is comforting to new parents."

Emily is a very busy first-grader, a Brownie who takes ballet and jazz lessons and is a cheerleader on a Pop Warner football team. Her favorite subject is math, and she's a good reader. She also has a distinctive fashion sense, favoring skirts, tops with fluffy flower appliques, boots and lots of different color combinations. "We call her our Sarah Jessica Parker," her mother said with a laugh.

She's also independent. If she wants to turn on the television, she grabs her stool and reaches for the buttons. If she wants to turn on the light in the living room, she brings her stool to stand on to reach the switch, even though her mother is sitting nearby.

"We have the same dreams for her that we do of our other daughters," she said, referring to Emily's younger sisters.

Much of that attitude comes from parents who don't shy away from accepting reality, while at the same time encouraging their children to achieve.

"Last year, Emily started to question why she was so small. Every morning, she'd wake up and ask, "Am I bigger today?" Michele Burke said. Despite the temptation to say yes, Burke said she focused on explaining to Emily that she was the size she is programmed to be.

"We try to help people break through the myths and denial, to explain they are destined to be 4-foot, 2 inches," Montouri said. "We also know that people will think of the Munchkins

(the famous dwarfs in the "Wizard of Oz") and we talk about how to prevent the child from falling into."

That honesty was how Robin Thibault raised her son Ryan, the middle child between two average-sized siblings.

"We always told him he was a dwarf; we don't shy away from the word," Robin Thibault said. "When he was 5 or 6, he was talking about who he wanted to be, and he said he couldn't be a mailman because he couldn't reach the mailboxes."

So much for denial.

The determination to achieve was something innate in Ryan, she said. "Even when he was little, he'd swing himself up on the kitchen counter to get something on his own," she said.

He obviously couldn't play football, so he managed the team. His doctor told him he couldn't play lacrosse, so he turned to wrestling. "What I like about wrestling is it's an individual and team sport at the same time. When you're out there, you're by yourself," he said. "I like the adrenaline, and it's a personal challenge: Not everybody can wrestle."

Minor adjustments, like pedal extensions on his 1995 Integra, a stool at the McDonald's where he works the counter, an extra set of schoolbooks at home, help Ryan live a regular teen life.

His efforts at school earned him a Character Counts award, presented to one student each marking period. His picture hangs in the main hallway, and many students wave or say hello to Ryan during an interview in the school's lobby.

Adolescence can be a pretty tough time for little people, said Raggio. "Being a person of short stature is easier when you're younger. When you hit adolescence, the whole idea of dating, getting out there, plays a big part."

For these teens and young adults, the Little People of America organization plays a big part, according to Daniel Okenfuffs, the vice president of public relations for the group.

"For a lot of people, one of the best opportunities is to come to an LPA convention. The 18- to 28-year-old members are strong on the dating scene," said Okenfuffs. He met his future wife at a convention, and after a transcontinental relationship between Washington, D.C., and California, he left his job as a lobbyist and moved to Sacramento, where he is a legislative assistant to a state assemblyman.

But more acceptance doesn't mean complete tolerance. Ryan said he encounters stares and sometimes offending comments (although not when he's out with his buddies from the football team).

"You just don't let it bother you," he said with a shrug.

There are also the health challenges he must deal with, like the surgery to straighten out the bowed legs many short-statured people develop. Ryan spent the summer in a wheelchair recuperating. In the future, he may need treatment for arthritis or lower back pain due to compressed nerves.

None of this will interfere with Ryan's plans to attend college, to study sports training or hotel and restaurant management, or to marry and have a family. Along the way, he too would like to be a role model for younger dwarfs.

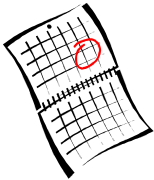
His mother believes he is. "I think the new parents of little people are in awe of him," she said.

"I hope I show people that they can do pretty much anything they want to. People who are more challenged than me get through life," he said. "I think you can find something to be thankful for every day."



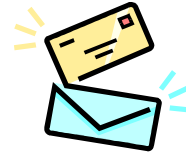
PATIENT SATISFACTION SURVEYS—YOUR OPINION IS VALUABLE

By now, many of you have been contacted at home to participate in our patient satisfaction surveys. We are interested in your feedback about your first visit to CSD as well as any follow up contacts with CSD. Please be assured that your answers are completely confidential. We value the feedback you provide us with as it helps us to know what is working well and what needs improvement. In our next newsletter, we will let you know the results of the surveys.



SAVE THE DATE

- ✓ **September 26, 2005**—CSD will host a celebration honoring Betty Adelson’s 2 new books, *The Lives of Dwarfs: Their Journey From Public Curiosity Toward Social Liberation* and *Dwarfism: Medical And Psychosocial Aspects Of Profound Short Stature* at Hospital for Special Surgery. Look for your invitation to arrive mid-August.
- ✓ **December 5, 2005**—annual CSD Holiday Party at Hospital for Special Surgery. This will be our third annual celebration. If the last 2 celebrations are any indication, this year’s soiree will surely be a festive way to start off the holiday season. Look for your invitation to arrive in early November.



THAT’S ALL FOLKS !!

This concludes our latest newsletter. We are planning to send newsletters twice a year to our patients and their families. However, just as with everything else, we would like your input. Do you have some thoughts, a story, some resources, or other useful information that you would like to let others know about? If so, please send them along to us. You can mail us at:

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