



The University of North Carolina Department of Physical Medicine & Rehabilitation
“Optimizing Health and Function through Excellence in Rehabilitation”

A CHALLENGE FOR THE BRAVEST HEART: YOUNG TEENAGER OVERCOMES HARDSHIPS, INSPIRES OTHERS

What makes children unique also can cause hardship. After suffering teasing because of our special qualities, many of us grow up still searching for the confidence to truly love ourselves.

For thirteen-year-old Jaclyn Young, however, acceptance of what makes her different – her cerebral palsy and her unique talents such as writing and speaking – came as early as age 11, and she has been inspiring others ever since.

In her deliberate and paced speech, and with the power of her pen behind the words, Jaclyn continues to share this message in her church and with others in her community:

You see, when I was born, I didn’t have a heartbeat for 15 minutes and I didn’t breathe for five minutes. Because of the lack of oxygen to my brain, a part of it was damaged. When I was six months old, my parents took me to a doctor and that visit changed my life forever. He diagnosed me with cerebral palsy. That is the reason I talk and walk differently than many of you. My parents were sad, especially when

the doctors told them that I may never walk or talk. Boy! Did I prove them wrong!

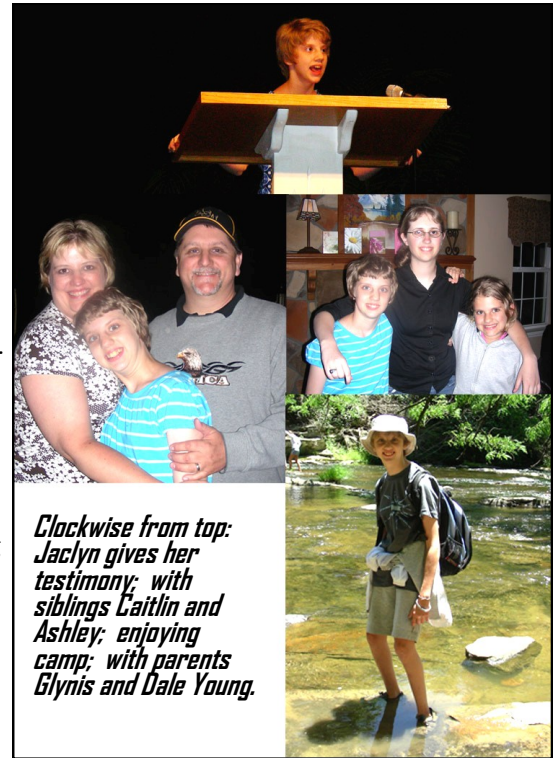
Now sitting in her own chair, within her “comfort zone” at home, Jaclyn relates how she frequently comes out of that comfort zone, something that has allowed her to stop asking “Why me?”.

“I love being around people,” she says. “I love talking. Cerebral Palsy is suffering. It is. But, at the same time, it’s also a blessing and I want to share that.”

Her mother, Glynis Young, confirms Jaclyn’s early resolve. After a difficult delivery, with six doctors helping to bring Jaclyn into the world, Jaclyn had a “miraculous turnaround.”

Mrs. Young explains: “Jaclyn went from needing a feeding tube, possibly indefinitely, to feeding on her own by the fourth day.”

At three years of age, the same girl who would “never walk” walked across a room without falling, and hasn’t stopped since.



Clockwise from top: Jaclyn gives her testimony; with siblings Caitlin and Ashley; enjoying camp; with parents Glynis and Dale Young.

⇒ Jaclyn Young’s story continues on page 2.

THE JOURNEY OF A CHILD ADVOCATE JENNIFER PFALTZGRAFF SHARES MOTIVATION, DETERMINATION



Jennifer and Ethan

You never know when your life will be touched or changed by a child with special needs, says Jennifer Pfaltzgraff.

When her second child, Ethan, was first diagnosed with cerebral palsy in 2004, the early intervention system was transitioning the program from county leadership to statewide. “We were on a waiting list to receive services,” she recalls.

While waiting for her son’s evaluation and services, Pfaltzgraff attended a talk by local agencies about free resources available to help families and children with special needs.

⇒ Jennifer Pfaltzgraff’s story continues on page 3.

Inside This Issue

CHAIR’S MESSAGE	2
THE TELABILITY PROJECT	4
EXTENDED ARTICLES ON THE WEB: THE TEAM APPROACH	4
CONTACT US	4

From the Chair

Michael Y. Lee, MD, MHA



Dear Friends,

I wish to thank the participants, volunteers, sponsors and donors who continue to contribute time, expertise and financial support for our Pediatric Rehabilitation Program.

Proceeds from events, such as our first Run Walk & Roll held in May 2009, help connect more patients to pediatric rehabilitation services around the state. (For more about this event and upcoming events in 2010, see our web site.)

We depend on your continued generous support for programs such as TelAbility, so that we may extend our services to many others, while excelling in our basic mission.

Our UNC Health Care Rehabilitation Center continues to restore function of patients significantly better than the national average for the same length of stay.

If you would like to partner with us by making a donation to carry forward our tradition of excellence, please contact our Director of Development, Nicole Pratapas: 919-966-8494 or nicole_pratapas@med.unc.edu by email.

Any amount will help all of our patients become more functional along the continuum of care.

Michael Y. Lee, MD, MHA
Professor and Chair, UNC PM&R
UNC Physical Medicine & Rehabilitation

⇒ *Juliellen Simpson-Vas, M.Ed. (left), TelAbility project director, and Joshua Alexander, MD, TelAbility program director, have saved families and therapists hundreds of hours and thousands of dollars in travel time and costs by using videoconferencing for clinic visits and educational programs. Proceeds from this year's Honours Golf Tournament, as well as your generous support, will sustain these critical activities, which are free to families and early intervention professionals. See story, page 4.*

JACLYN'S STORY (FROM PAGE 1)

Jaclyn credits her supportive family, including grandparents living just down the road, a church that includes her as an equal, and a pastor who wrote a book about his own cerebral palsy, as factors shaping her brave persona.

Her younger sister Ashley, also sitting in her own chair, recalls a time when she defended Jaclyn in front of a peer. "Jaclyn was writing on the board and when I heard a girl teasing my sister because of the way she writes, I said, 'You shouldn't say that just because she's different.'"

Jaclyn's older sister, Caitlin, also mentors Jaclyn to do her best, as does her encouraging dad, Dale Young.

Jaclyn and her family also credit Joshua Alexander, MD, her physiatrist in the Department of Physical Medicine & Rehabilitation.

"We have really benefited from Dr. Alexander's coordinated approach to care," Mrs. Young says. "We have found a lot of programs and therapies we didn't know about. It's also comforting having that second opinion, and to have a coach to help us deal with issues as a family."

Jaclyn agrees. "I really trust Dr. Alexander. He has taken me step by step to my next goal and doesn't rush."

Most importantly, Jaclyn is motivated by her own faith, as she also writes in her testimony: "Sometimes, it hurts when someone who doesn't understand me might laugh at me, but God knows how I feel, and it makes me more determined to do my best."

Her mother inspired Jaclyn at an early age to have compassion for others enduring hardship. When Jaclyn had to wear an awkward hip brace, Mrs. Young recalls: "I felt as though people were judging me for that." She once saw another mother with a child in the same brace, enduring harsh stares from passer-bys. She approached the mother and said, "My baby had to wear one of those, and it's going to be OK."

Mrs. Young also started her own support group when she couldn't find the right fit, remembering kind advice from a parent who once helped her. "It's important to give back," she says. "That can be a lifeline in the beginning. My advice for parents looking for support groups would be if you can't find one, start one."

Following in these footsteps, and with her peers in mind, Jaclyn educates others who "are afraid and uncomfortable" around children with special needs. Once, a six-year-old

boy asked her, "What's wrong with you?" Jaclyn, who also was six at the time, replied, "Nothing. What's wrong with you?"

When the family went through probably the most severe period of teasing from Jaclyn's peers, her mother prayed for relief of suffering for her daughter. Soon after that, she heard a sermon about an apostle asking God to end suffering, and the reply that His grace was enough. Mrs. Young later thanked her pastor for the insight in a letter, because it also had helped Jaclyn understand her life's purpose.

"He wrote back that his greatest joy is helping those in the valley of despair with a spirit of waiting and worship," Mrs. Young quotes from the letter. Having now passed through grief and anger herself, Jaclyn continually shares her boundless courage and advice. Even as she makes plans to go to a college and write her story as a book, she keeps an eye on her present tasks.

"I like to give people challenges, to help them step up," she says. "I challenge them to get to know individuals with special needs, to get to know me."

"I want to be seen as just a normal teenager, to fit in," she continues. "When people do see me for who I am now, with my courage and confidence, I'd like them to know that comes from my faith and not anything I have done."

JENNIFER'S STORY (FROM PAGE 1)

“We didn’t know what was out there for Ethan,” she remembers. “We didn’t even know what ‘out there’ was.”

Pfaltzgraff and her husband Jim learned an important lesson from the talk: to be assertive versus aggressive, in order to get a message across in a positive way. Pfaltzgraff notes, “Now I always ask, ‘What can I do to speed this along?’”

While continuing to navigate the state system, Pfaltzgraff began to realize the power of communication and networks, such as the TelAbility program in the UNC Department of Physical Medicine & Rehabilitation.

“TelAbility is a wonderful example of a network created through technology and communication,” Pfaltzgraff says. “It can expand to families without computers as long as the caregivers and educators have computer access. TelAbility also could expand to other counties, states and nations, helping families see the big picture.” She also sees the potential for TelAbility to connect children to resources that will help them later as adults. “As children grow, families still need sup-

port systems and networks. If these networks are woven carefully and expanded in the future, families will never feel left out."

With weaving this social fabric in mind, Pfaltzgraff also helps in other organizations. She started volunteering with the Wake County Local Interagency Coordinating Council (LICC), contributing as a parent advocate and by using her skills in computer design and marketing. She now serves as parent co-chair, collaborating with other parents and professionals to educate the community about the importance of early intervention.

Pfaltzgraff helped develop the Early Intervention Highway graphic (below) as part of an educational booklet, so that others could see “what’s out there” and when. She also joined The Arc of Wake County, currently serving as president of the board of directors. She helped to develop Family Fun Night, a joint program with the Marbles Kids Museum. Every second Wednesday of the month, the museum hosts a play time entirely for children with special needs. “I remember one parent whose daughter

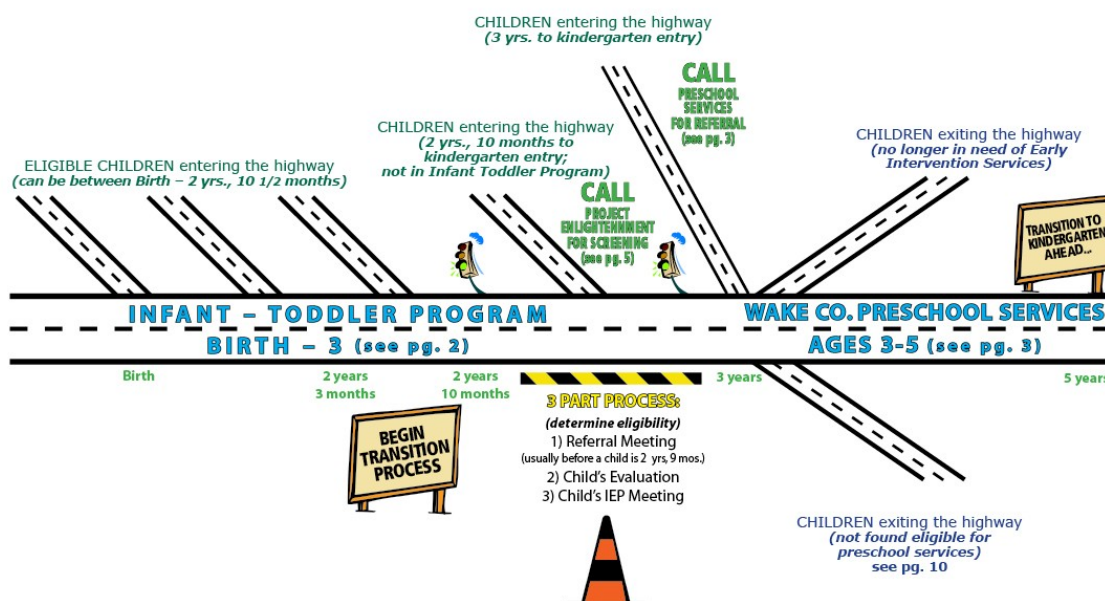
had fragile bone syndrome and used a walker for safety,” Pfaltzgraff recalls. “The parent said this was the only way her daughter could go to the museum. On other days, the museum would be too crowded.”

As an advocate, Pfaltzgraff has come away with even more lessons. "If I could teach parents one thing, it's this: the more families know, the easier their job will be as a parent of a child with special needs," she says.

Pfaltzgraff is careful to balance her family life with her efforts in advocacy, making sure to spend quality time with her entire family. "I can't do it without my husband Jim, nor my 8 year-old daughter, Madeline. My family is my inspiration."

When asked how she keeps going: “It boils down to maternal instinct really,” she says. “It’s partly an unconscious effort. If a question arises, we look for answers. But it’s not always easy, so we use all of the great resources, like TelAbility, to find that answer. It’s all about advocacy, collaboration and communication.”

The Early Intervention Highway



and what's up ahead...

Jennifer Pfaltzgraff spoke at our 2008 Honours Golf Tournament, which raised over \$7,000. Proceeds from the tournament will help children with special needs via TelAbility, a program in the UNC Department of Physical Medicine & Rehabilitation.

As Dr. Lee states in his message, the future of TelAbility depends on your generous support in order to continue current services and to expand in ways suggested by Jennifer Pfaltzgraff in her article. Current funding will end in 2010.

⇒ See next page for more about this important program and consider making your gift.



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TelAbility regularly holds videoconferences on a variety of topics for children with special needs. Photo courtesy of John Rex Endowment/by Billy Barnes.

nities to discuss care with professionals via community teleconferences and a chance to browse and print an array of educational materials.

The Wake County Services and Resources for Children 0-5 assistance webpage found on www.TelAbility.org is one of many advances made possible through county-wide collaboration and support from local funding agencies and endowments.

The program's founder, Joshua Alexander, MD, of the UNC Department of Physical Medicine & Rehabilitation, hopes to duplicate this service in other North Carolina counties, but money from the endowments is drawing to a close.

"We are in debt to the Duke Endowment, the John Rex Endowment and Wake County Smart Start for providing funds to begin and to support the TelAbility Program," Dr. Alexander says. "We are looking for funding not only to continue at our current level, but to expand across North Carolina to locations with fewer resources, such as rural areas."

Juliellen Simpson-Vos, the program's project director, notes that the program has become an "integrated part of parents' and professionals' lives." The program now includes over 732 experts in its directory. In 2000, the program held three videoconferences; today the program holds over 50 videoconferences a year with close to 1,000 participants.

"Our service makes navigating the early intervention system more personal," Simpson-Vos notes. "When parents ask questions on our site, they get several emails answering those specific questions, sometimes within minutes."

Families connect to a statewide community, browse educational information, and join support groups. In addition to the benefits of the web site, TelAbility uses real-time videoconferencing to offer clinics and consults which improve care coordination for a child and save families thousands of dollars in travel costs.

TelAbility also hosts state-wide, interactive discussions on new therapies, medical resources and assistive technology. The videoconferences allow early intervention service providers to communicate with each other, widen their knowledge base and increase their circle of influence, often without having to leave the comfort of their offices.

"We continuously cut through the red tape by connecting people directly to each other and by providing credible, reliable resources at people's fingertips," Simpson-Vos adds.

For the parent of a child with special needs, connecting with this community means replacing anxiety with empowerment.

**QUESTIONS? GO TO
WWW.TELABILITY.ORG
FOR A HOST OF ANSWERS!**

Q: I just found out that my baby son has cerebral palsy. The doctor said I could expect delays in development, and my son will need constant support. What can I do?

A: These days help for parents of a child with special needs is only a few clicks away, whether using a computer at work, home or the office of a health care provider.

By selecting the child's age, the region, and the services needed using a tool for Wake County on the TelAbility web site, this parent would receive at least five responses shortly, as well as opportu-

Look for extended articles on our web site:

www.med.unc.edu/phyrehab/peds-issue-extended

- ⇒ Caring For Children Takes A Team: The Advantage of Our Interdisciplinary Approach in Clinics
- ⇒ Dr. Alexander Mentors about the Importance of Trust
- ⇒ Understanding Different Therapies for Children (as reported in *Rehab Management*)

Please consider making a donation to TelAbility or other services by contacting Nicole Pratapas: 919-966-8494, nicole_pratapas@med.unc.edu via email, or by secure donation on our web site. Thank you for your gift!