Jake succeeds on his own terms

It was a shock to Jake Zweigbaum’s parents when they learned that their nearly four-year-old son had a severe hearing loss in his right ear. “Jake was talking in sentences at 11 months, before he could walk,” his mom, Elly, explained. “When he wanted to put the phone to his left ear and said he couldn’t hear in his right ear, we had a hard time believing him.” Jake was tested, diagnosed, and fitted with a hearing aid.

Later that year, Lynn Dennis, who coordinates PACER’s Puppet Program, was performing in a puppet show at the Adath Jeshurun Congregation’s preschool. Though it was more than 16 years ago, and Lynn has performed in many shows since, she remembers this one vividly. “Jay, the puppet with a hearing aid, was demonstrating it,” she said. “A little boy jumped up and said, very excitedly, ‘I’ve got one too, it’s blue!’” That boy was Jake.

The puppet show was Jake’s first encounter with PACER Center, but it wasn’t the last for the Zweigbaum family. Shortly after attending her first PACER Benefit, Elly began to serve on PACER’s Advisory Board. As a high school student, Jake was a member of the Youth Board for PACER’s National Bullying Prevention Center. Jake also took advantage of assistive technology through PACER’s Simon Technology Center. “One of the cool things about PACER Center is that it normalizes disabilities,” Jake said. “I really respect that. Everyone just wants to be treated the same.”

Today, Jake is a confident young man who has developed self-advocacy skills, but it hasn’t always been smooth sailing. “A teacher didn’t want to believe he was deaf in one ear,” Elly said. “She said, ‘He keeps turning around.’ She suggested he had ADHD (Attention Deficit Hyperactivity Disorder). Jake was turning so he could read lips when people spoke.”

While Jake is comfortable with his disability, not everyone is. “When I meet people, I have to explain. I’ve had people say, ‘you don’t sound like a deaf person.’” He often has to tell people multiple times that he is deaf in his right ear. “Miscommunication is a frustration of mine, and sometimes people get frustrated with me. Sometimes I get severe migraines, I have sensory issues when I go to concerts or events.”

That is especially difficult for Jake, because music is his passion. “I’m very musical,” he said. “In high school, I played guitar and sang in bands. I was a big theatre kid.” When it came time to apply to colleges, Jake wanted to follow his passion. Continued on page 7

“One of the cool things about PACER is that it normalizes disabilities. I really respect that. Everyone just wants to be treated the same.” - Jake Zweigbaum
PACER’s grandparent-to-grandparent group

Grandparents often play a significant role in the family of a child with a disability, lending strength, love and support. While there are services in the community for children with disabilities and their parents, few exist to meet the needs of grandparents. PACER stepped in to fill this void.

PACER’s grandparent group meets every month or two during the school year. Members gain more knowledge about their grandchild's disability and available services. Due to the pandemic, the group currently meets virtually. The meeting format varies. An expert may speak; they may watch a relevant film, and once or twice a year, the group holds a potluck social.

At their last meeting, the group discussed disability-friendly social outings for grandparents and grandchildren. At their next meeting, they will watch the groundbreaking documentary “Intelligent Lives,” which features three young adults with intellectual disabilities as they challenge stereotypes.

Recently, parent advocate Maleenia Mohabir of PACER's Children's Mental Health and Emotional or Behavioral Disorders Project helped problem solve behavior issues. She advised, “Rather than thinking, ‘I don’t understand why my grandchild won’t participate in this activity or won’t do what they’re supposed to,’ realize that sometimes, they can’t.”

At another group meeting, PACER parent advocate Linda Goldman Cherwitz discussed transitioning from high school to work, various educational or vocational programs, and issues such as housing, and guardianship or conservatorship.

The group is very supportive of new members. “When a new ‘grand’ joins, everyone wants to hear about their grandchild and what they’re experiencing,” said PACER's Susan Einspar, who coordinates that group. “It’s a lovely, supportive environment. All of the grandparents are very understanding and kind.”

Grandparent group members:

Cathy and Bill Milota

After Cathy and Bill Milota’s daughter Kristin and her husband, Mitchell, adopted their baby daughter, Jackie, who has Down Syndrome, the Milotas joined PACER Center’s grandparent group. Cathy is a former PACER employee who coordinated the puppet program. “The grandparents’ group is very welcoming to all,” Cathy said. “People are so friendly.”

Though Kristin and her family live nearly 1,000 miles away, in Dallas, that hasn't prevented Cathy and Bill from being close to their granddaughters. Jackie, who is now five, has an older sister, Alora, who is eight. “Before the pandemic, we visited them twice a year and they visited us twice yearly, too,” Cathy said wistfully. “We enjoyed traveling together.” They treasure their memories of Jackie pulling Bill by the hand, saying, “Come, Papa!” and of her singing as her father played guitar.

“Like many grandparents, we want to share the information we learn with our children. It’s fine to share information, but you have to be careful not to give more advice than your children want to receive,” Bill said. He added, “We also provide some support when group members ask for help or share problems.”

Bill and Cathy agree that they truly prize the time they spend with the other grandparent group members.
When PACER’s National Bullying Prevention Center held its first Run, Walk, Roll Against Bullying 11 years ago, a few hundred people showed on a crisp October day to support bullying prevention. They walked, ran, and rolled along a course, cheered on by supporters.

The Run, Walk, Roll Against Bullying became a popular annual event, held at Normandale Lake Park in Bloomington, Minn., during National Bullying Prevention Month in October. It featured a range of speakers, entertainment, celebrities, and refreshments. Businesses, individuals, families, and teams participated.

Last year’s event was cancelled when the global pandemic hit. This year it resumes, with a few twists that make it even more exciting and inclusive. “This year’s Run, Walk, Roll Against Bullying is virtual, and that means people around the world can participate,” said Julie Hertzog, Director of PACER’s National Bullying Prevention Center. “It’s much bigger than coming to Bloomington on a particular day—the event runs during the entire month of April. Everyone can participate and tailor participation to fit their schedules.” In keeping with the universality of this year’s Run, Walk, Roll Against Bullying, PACER has set a collective goal of 24,901 miles: the circumference of the earth.

This year, there are endless ways to participate. Individuals can set goal miles and complete them in one day, a few days, or over the entire month. Friends and family members can dedicate a day to walk or bike together, socially distanced or at separate locations. Groups, such as a school or business, can form a team with members participating in their own way throughout April and recording collective miles. Participants can be creative in how they want to support the event, such as making a donation for every mile recorded. While it’s free to participate, contributions are encouraged.

“Participants can donate, or ask others to sponsor them,” Julie said. “The proceeds go to support the free services we offer to youth, families, and educators.” Corporate sponsorships are available; another great way to support is to purchase 2021 event merchandise, with proceeds going to PACER’s National Bullying Prevention Center. T-shirts are $25, bandanas are $10, and wristbands are $5. An event package including all three items is $30, all prices include shipping.

Most important is that as many people as possible participate, Julie said. “Every mile contributed matters and will move us closer to reaching our goal of circling the world to make it kinder, more accepting, and more inclusive of all.”

**WHEN:** April 1 – 30, 2021

**WHO:** Everyone!

**WHERE:** All communities around the world

**HOW:** Set a goal of miles, to achieve in one day or during the month, by walking, running, rolling, strolling, biking, hiking, or wheeling, either indoor or outdoor

**REGISTRATION:** Free!

**MORE INFO:** PACER.org/RWR
Giving to PACER & receiving a tax break

Most people contribute to PACER because they believe in its mission and want to help families of children with disabilities and all children who are bullied, but it’s also important to know about the great tax benefits available to donors. PACER offers the following for informational purposes only, and encourages you to consult with your tax advisor.

- **Non-itemizers.** Under the CARES Act (new tax law), in 2021 you are eligible for a tax deduction of up to $300 for single filers or $600 for married couples who file a joint return. This deduction will reduce both your adjusted gross income and your taxable income, thereby decreasing the amount of federal income tax you owe.

- **If you itemize.** The limits to how much you can deduct are higher than usual in 2021. If you’ve been thinking about making a gift that is larger than usual for you, this might be the best year, tax-wise, to do so. Consult with your tax advisor to plan this to your best advantage.

“Bunching” your donations if you are close to reaching the standard deduction is another way to realize significant tax savings. “Bunching” is making a larger charitable gift or gifts every other year. You may want to consult your tax advisor about using it to your advantage if your combined state and local tax, home mortgage interest, and charitable gift deductions are close to the standard deduction. Making larger charitable gifts every other year could be an excellent tax-saving strategy.

Donating appreciated stocks and securities may work well for you if you give them directly to PACER Center. This allows you to deduct the full value of your gift. PACER can provide you with easy-to-complete forms for this purpose.

**Make a tax-free gift through IRA distribution**

If you are age 70½ or older and have a traditional (non-Roth) IRA (Individual Retirement Account), you may make yearly gifts totaling up to $100,000 to PACER Center to satisfy your annual required minimum distributions. Contributions made directly from your IRA to a qualified charity like PACER Center by December 31st are not taxable to you, and your gift is not taxable to PACER. You do not have to itemize in order to make a tax-free gift. It’s important to follow IRS rules for charitable IRA rollovers (also called qualified charitable distributions, or QCDs), and to consult your tax advisor before completing a charitable IRA rollover.

**Ways to donate**

- Donate securely online at PACER.org/help/donate.asp
- Call (952) 838-9000 to donate via credit card
- Mail a check to PACER at 8161 Normandale Blvd., Mpls., MN 55437-1044
- Questions? Contact Paula Goldberg at (952) 838-9000

Sign up for AmazonSmile today and support PACER while you shop

Amazon.com will donate a portion of the price to PACER every time you shop through the AmazonSmile program at no cost to you!

To sign up, visit [smile.amazon.com](http://smile.amazon.com), select “get started” and sign in with your email or cell phone number. Name PACER Center as your beneficiary, and Amazon will donate 0.5% of your purchases to PACER. It’s a quick and easy way to support PACER!
Beth Simermeyer is connected to PACER in three ways: through her volunteer service on the Board of Directors; as a donor; and as someone who uses PACER’s services.

“PACER is so important to families who have children with special needs,” she said. “It’s not always easy to figure out your rights and your children’s educational rights. PACER helps all families, including those whose language, culture, or skill set make it more challenging to leverage their rights.”

Beth, is a single mother with three children with special needs, all of whom she adopted from Russia. Shortly after she relocated to Minnesota seven years ago to take a job at Ecolab Inc, a co-worker who went to school with Paula Goldberg’s late son, David, introduced them. “I used a number of PACER’s resources for my children, and Paula invited me to join the Board of Directors.”

Beth has served on PACER’s Board for five years now. “It’s a wonderful Board,” she said. “After I moved to Minnesota, PACER Board members were some of the first people I met in the community who weren’t co-workers or connected to my children’s schools.

“Everyone on the Board has a connection to special needs. A number of us have children with special needs, and some have siblings with special needs. At every Board meeting we talk about why we’re part of PACER. It’s a committed, passionate group of people,” Beth said.

“Mine is a three-generation family,” she said. Her 92-year-old father lives with her, and their household also includes four dogs and two cats. Her work life is equally full: she is executive vice president and president of Healthcare and Life Sciences at Ecolab. “I lead the group that is in charge of hospitals and pharmacies,” Beth said. “The last year has been quite a wild one.”

She is quick to say that her life is a bit easier now that her two older children are young adults and driving. Jack, 20, attends the University of Puget Sound, and Caroline, is a senior at Minnetonka High School. Her youngest child, Liam, is 14, and is also in school in the Minnetonka district. “Even though I have help and have built a good support system, there was a good ten years when I had almost no time for myself,” Beth said.

She is a proud mother. “Jack has worked hard to transform himself as a student,” Beth said. “He is most interested in politics and education and has talked of running for office or maybe becoming a history teacher.

“Caroline has two horses and loves to ride. She also trains younger kids and competes.” Caroline volunteers at an organization that offers therapeutic horseback riding for people with disabilities. “She puts her younger brother on a horse. That’s really good for kids with autism. Caroline plans to attend a community college, majoring in equine management.”

Beth’s youngest son, Liam, is on the autism spectrum. “Liam also has apraxia and is largely non-verbal,” Beth said. “He’s had a lot of delays, complicated health problems, including two heart surgeries. It’s a lot for a kid of 14.” PACER has helped Beth to plan for Liam’s future. She said that PACER’s seminar on special needs trusts was very helpful. “I learned some important information to help him live his best life post-school.”

Beth said it helps to know that PACER will be there for her family and other families. “PACER does such important work. It’s rewarding to me to support PACER however I can.”

Beth pictured with her children Liam, Caroline, and Jack.

“Beth is amazing in so many ways. She has wonderful empathy for families of children with disabilities and is dedicated to helping them— and to helping PACER.”

- Paula Goldberg, PACER’s Executive Director
When PACER staff first began to work remotely more than a year ago, there were more questions than answers about how services like workshops, puppet shows, and school meetings would work in a virtual format. Inevitably, there were surprises and a learning curve, but PACER’s dedicated staff stepped up and made changes and improvements to programs, with the needs of families at the forefront of everything they did.

Virtual programming, especially of workshops, was one of the biggest shifts in how PACER serves families. Jamie Smith, PACER’s network administrator, took on the role of producer and technical expert, coaching staff through trial runs, helping get virtual events up and going, explaining technology, troubleshooting problems, and being available to iron out problems as they occurred. “Some staff, including those of PACER’s Simon Technology Center, were able to produce their own videos and workshops,” Jamie said, but many relied on his expertise to be able to deliver virtual and interactive programming to families.

It’s not surprising that PACER’s Simon Technology Center (STC), with its tech-savvy staff, was able to adapt to serve families virtually. “The biggest thing we realized was that making changes to our services in response to the pandemic has actually improved them,” said STC Director Terri Rosen. “It’s all about accessibility.”

One of the STC’s biggest successes was moving assistive technology consultation to a virtual platform using Zoom. “We’ve had such a positive response to the adaptation to an online consultation service,” Terri said. “While some types of consultations and assistive technology work better with in-person demonstrations, we’ve realized that using Zoom has actually expanded our ability to work with families and made it a more accessible service for a wider array of people.” People who live in the far corners of the state and would have difficulty traveling to PACER under normal circumstances, those who lack transportation, or those whose health or disability made in-person appointments challenging have benefited greatly from virtual appointments, Terri said.

PACER’s National Bullying Prevention Center expanded its resources to meet educator and student needs, including adapting its year-long ALL IN curriculum for educators to deliver virtually. “The majority of our resources are already accessed through our website,” said Julie Hertzog, Director of PACER’s National Bullying Prevention Center. “To meet the needs of remote learners, we set up more digitally interactive opportunities to engage students at home, such as book readings, slide-shows, videos with customized worksheets, and infographics.”

PACER senior parent advocate Susan Einspar remarked that by using virtual platforms, advocates were able to attend more school meetings with parents. “Advocates have a broader reach,” Susan said. “We can be more efficient with our time. We are able to attend meetings virtually that we couldn’t in person. There were some meetings that we previously attended over the phone that we now attend using Zoom or a school’s virtual platform. It works out beautifully; you have more genuine conversations when you can see the person’s face.

“There were times when advocates weren’t able to attend a meeting because it was too long a drive or the roads were bad in the winter. Those aren’t barriers when you attend virtually. Parents feel more supported when we can participate. They don’t feel so overwhelmed like they did when everyone was there but their advocate.”

PACER parent advocate Deanne Curran, who works with many parents and transition-age students who are deaf, deaf-blind, and hard of hearing, said that one advantage to virtual meetings with schools and parents during the pandemic is that educators, who often have children at home learning remotely, are now willing to meet virtually outside of regular
school hours. “This is helpful to working parents,” Deanne said. “I’m able to sometimes adapt my hours to make this work, whether it’s meeting before they start work or later in the evening.”

Deanne added, “Doing our workshops virtually was often a win/win situation; since I wasn’t driving to greater Minnesota, I had more time to attend virtual meetings and workshop attendance was often up because parents could easily log in, rather than driving to a workshop.”

**Multicultural families face challenges**

While some families have adapted well to virtual communication, that hasn’t been the case for many of the families served by PACER’s multicultural advocates, who are used to the cultural expectation of meeting face-to-face in their homes. Advocate Dao Xiong, who works with Hmong families, explained that an important part of his work is being visible in the community. “Families need to see me and know who I am so they can ask for help or refer other families to me,” he explained. “Now, there is no way for me to be at events like I used to do,” he said. “It’s also challenging because before, I could go to a family’s home and they could show me documents from the school.” With language barriers, many families didn’t know the difference between documents; Dao could help them sort through and find the right one. “Now, I cannot visit homes. I can ask them to scan documents and send them, but many don’t. They don’t have the equipment, or don’t know how to do this or don’t know which document to send.” Dao and other multicultural advocates find themselves providing technical assistance and encouragement. “Sometimes parents are able to understand, but it is a struggle,” Dao said.

To learn more about how other PACER programs have adapted to the pandemic, visit [PACER.org/adapts](http://PACER.org/adapts) which includes interviews with staff from PACER’s Children’s Mental Health and Emotional or Behavioral Disorders, Transition, Puppet Program, Health Information Center, and Minnesota Statewide Family Engagement Center programs.

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When he told his parents he wanted to attend Berklee College of Music, one of the country’s preeminent music schools, they were worried he would not be accepted.

“We told him, ‘Don’t put all your eggs in one basket,’” Elly said. “Jake is a self-taught musician. He had never had any music lessons. He practiced every day with YouTube videos. We had no idea how talented he is.”

Today, Jake is a junior at Berklee, majoring in music business with a minor in production. He loves pop and R&B and has a strong entrepreneurial streak. “I hope to start my own music production company,” he said.

Jake offers this advice for people with disabilities: “I was told, ‘you can’t do this class because you can’t hear.’ I don’t let that stop me. Don’t let other people tell you what you can or can’t do. “You may have to struggle to be understood. You may be discriminated against. That might never go away, but it always makes you stronger.”

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“**The biggest thing we realized was that making changes to our services in response to the pandemic has actually improved them.**”

- Terri Rosen, PACER’s Simon Technology Center Director
Dear Friends of PACER,

I wanted to take this opportunity to share with you how grateful I am for the support of PACER’s Board of Directors, other volunteer boards, and the members of our community who have supported and contributed to PACER over the last year. This has been a difficult year for all of us.

I also want to recognize the hard work of PACER’s staff, most of whom have worked remotely during the pandemic. The staff has been tireless in responding to the many calls and emails from parents who struggled to make distance learning work for their children. PACER’s staff have all dedicated themselves to creating materials for our website, have produced and recorded amazing workshops, and have been there at a time when parents have needed them most.

When we look back on this time, I hope we will remember not only the hardships we faced and the losses we experienced, but also those who selflessly stepped forward to help. On behalf of the families PACER serves, thank you all so much.

Sincerely,

Paula Goldberg
Executive Director, PACER Center

A Note from Paula