

gizmo

THE TETRA SOCIETY OF NORTH AMERICA: CUSTOM ASSISTIVE DEVICES

BUCKLING UP FOR A SAFE RIDE THROUGH LIFE



FAMILY ALBUM: SNAPSHOTS, TAKEN OVER THE PAST TWO YEARS, OF CONJOINED TWINS EMMA AND TAYLOR BAILEY, SEEN HERE RECENTLY WITH OLDER SIBLINGS COLE, DREW AND PAIGE [LEFT]; AS NEWBORNS; SITTING, UNAIDED; AN EARLY, UNFINISHED, PROTOTYPE OF THE TETRA CAR SEAT.

— BY MATTHEW WILD, DISABILITY FOUNDATION —

SALT LAKE CITY: The mother of 22-month-old conjoined twins turned to the Tetra Society for a car seat that would enable her to safely transport her children.

Emma and Taylor Bailey were born Sept. 20, 2006, joined at their tummies—conjoined from clavicle to sternum—sharing a chest cavity, heart and a liver. Medical staff did not expect the girls to live.

Parents Mandy and Tor Bailey, of Queen Creek, Arizona (37 miles southeast of Phoenix), were told to expect every moment with the newborns to be the last. Emma and Taylor share a single-ventricle heart—one of the heart's pumping chambers does not function.

Now nearly two, the girls are continuing to confound the experts. In March of this year they sat unaided for the first time. Within the past few weeks they have become mobile, getting around the house in a walker, trying to get into kitchen cupboards and doing the things toddlers do.

For mom Mandy—who gave birth to a healthy six-pound baby boy, Blake, on April 21 after a pregnancy

that included five weeks confined to hospital—this last two years has been an emotional roller coaster.

“There has been something of everything,” she said. “On the day the girls were born, we were so thrilled to get to that point. We had been told over and over that they might not survive birth

“When they were one year old, their cardiologist told us that babies with a single-ventricle heart are not expected to live beyond six months. Having two babies on a single, abnormal heart, that are growing, is breaking all the rules.”

The family has three “absolutely major” items of adaptive equipment: a walker, stroller, and the Tetra car seat. The former allows

them to move around the home, the other two enable trips outside.

“It was apparent last month that Taylor is absolutely done with lying down,” she continued. “They can move themselves by themselves, getting all four arms down on the ground. But it’s limited. They get their arms stuck. Their coordination is not there yet.”

Before receiving the car seat, the only way to drive the girls was in a metal-framed basinet, wrapped in a seatbelt. “From six months they did not fit in it. They were squashed and angry. Our cardiologist is an hour-and-a-half away. Car rides were miserable.

“The car seat has made a huge difference. What they came up with

was fantastic, and doing it just for us was so delightful.”

Tetra’s Salt Lake City chapter, made up of volunteers from Autonomous Solutions Inc, handled the project. Coordinator Kent Remund explained that the family wanted a design that involved the girls lying down. He took measurements and created prototypes to show the family various alternatives. The hard work was in the planning, he said.

“We ended up using a type of ABS plastic that is used for bicycle helmets. We spent a long time creating it, although when it was finished it is a very simple contraption—a flat piece of plastic with sides that come up, with slots in a few different places for straps.

“I offered to make them another for when they are stronger, that will allow them to sit in the car.”

That will likely be the next step, said Mandy. She is determined to have as normal a family life as possible, having, in addition, three older children: Cole, six, Drew, eight and nine-year-old Paige.

Hope ahead for conjoined twins

All the way along, Emma and Taylor Bailey have been confounding medical experts. Now parents Mandy and Tor are daring to think the unthinkable: having the girls surgically separated. This has been made an option up-to-the-minute advances in artificial heart technology. In early June they heard that specialists in Seattle saw “reason for discussion” about the procedure, and will bring surgeons and the family together for tests and consideration of the risks. Emma and Taylor have been followed by a Discovery Channel documentary team, which expects to air the documentary in the fall. For more info see the family blog: emmaandtaylorbailey.blogspot.com.

Tetra Society: Coast-to-coast innovation for people with disabilities

Volunteers recognized at Tetra awards night

VANCOUVER: Tetra Vancouver's volunteers recognized by their peers and clients, at an award show in the city, in May.

The "Gizmo Awards" highlighted the most innovative projects from the city over the previous year, chosen by a panel of Tetra volunteers.

Winning projects included a device to enable a quadriplegic to empty his bladder, a guitar strummer for a stroke victim, a bocchia ball holder, a Surrey schoolgirl's adapted desk and an automated floor platform.

Other projects were on display around the room, ranging from the kayak modifications that enabled adventurer Brad Jacobsen to tackle BC's notorious the Juan de Fuca Strait to an extendable, portable shoehorn.

Award winners included:

Quality of Life Award:
David Doman and Jay Drew
(Bladder Tapper)

Most Creative Solution Award:
Marvin Pflug (Guitar Strummer)

Community Impact Award:
Brian Johnson (Bocchia Ball Magazine)

Best Children's Project Award:
Marvin Pflug (Adapted Desk)

Sam Sullivan Award:
Greg Mills (Floor Raising System)

Service pins for 25 projects:
David Doman, David Graham, Marvin Pflug

"These inventors are invaluable to people with disabilities in Metro Vancouver," said Tetra executive director Duane Geddes.

"Their innovations create new possibilities for greatly improved quality of life."

The Vancouver area Gizmo Awards were held at Telus World of Science on Thursday, May 1, 2008. An audience of 140 attended.



IN FOCUS: VANCOUVER'S MARVIN PFLUG TALKS TO THE MEDIA ABOUT THE ADAPTIVE DESK HE MADE FOR EMMA VAUGHAN.

INTERVIEW WITH THE VOLUNTEER:

Mike McNally, Tetra Hamilton, ON

TETRA HAS MORE THAN 200 VOLUNTEERS ACROSS NORTH AMERICA, WORKING ON A VAST RANGE OF PROJECTS—THIS ACCOUNT IS FROM JUST ONE..

He's worked on highly technical and high profile projects, but Mike McNally's great pride is the design of a crib door for a severely disabled young boy.

His satisfaction comes from "taking it another step"—thinking laterally to come up with the best solution to a challenge. Natural ingenuity beats over-complicated engineering every time, he says.

Not that McNally has anything against the complicated route. He personally devoted an estimated 150 hours (although he politely declined to put a figure on it) last Christmas, as part of a team of elite engineers working on a rather high profile access problem.

Ontario's Ministry of Natural Resources asked Tetra to devise a solution to enable people with significant disabilities, including Lieutenant-Governor David Onley, to access official airplanes. The team—which also included Craig Brewer, Ali Taha and Sam Barnes, all of Peel chapter, and Tom Richardson, of Hamilton—devised a folding ramp to take Onley up into the ministry's nine-seat Hawker Beechcraft 350 aircraft.

Closer to McNally's heart is a young client, who had outgrown his adaptive crib. Although one end swung open, it was difficult to lift him in, and a side opening was required.

It would have been 'easy' to install a hydraulic system—but harder to reach a 'simple' solution. Thinking laterally, McNally used a thick but flexible plastic panel that is held tight by a roller.

"The side of the crib was 80-mm clear PVC, the type they use in supermarkets to cover the freezers, with an aluminum bar at the top, and a roller at the bottom," he explained. "When you give the roller a twist it tightens the side. The boy could not push the plastic out."

His current project is for a client looking for a way to hold a cane on his wheelchair.

"He had been thinking of using an adaptation to a mop holder—what you would use to hang a mop on the wall," said McNally. "But...I got to thinking about magnets.

"There's an outfit called Magswitch that will hold 90 pounds, but release completely with a twist of a knob. I put a metal bracket on the side of his wheelchair and mounted the Magswitch on the side of the cane.

"When you turn that switch on you cannot pull that cane off."

Another memorable project of his was a tennis ball launcher that enables a nationally ranked wheelchair tennis player to practice his serve, based on a caulking gun with a spring added.

Hamilton coordinator Sylvia Baliko praised McNally's "commitment to Tetra" adding that he "completed five projects over the past year, along with being the main force behind the platform lift for David Onley."



Statistics Canada

REPORT FINDS ASSISTIVE DEVICE COST AND AVAILABILITY ARE A BARRIER TO MANY

A Statistics Canada report showed that people with disabilities often lack assistive devices because of high costs.

The Participation and Activity Limitation Survey, released in early June, measured unmet needs of the 4.2 million Canadian adults with disabilities. Of these, 2.7 million people required assistive devices each day – 9.9 per cent had none of the necessary equipment, and 28.9 per cent did not have enough.

The cost of purchasing or maintaining assistive devices was the most frequently cited reason for unmet needs, followed by not knowing where to obtain them. Those with the most severe disabilities were least likely to have all their needs met.



A NEW CHAPTER: TETRA CALGARY CLIENT HELEN ROJEK (RIGHT) WITH HER UPGRADED SIP 'N' PUFF COMPUTER EQUIPMENT; VOLUNTEERS (FROM LEFT) NICOLA BIRCHALL AND BRAD CLEMENTS; STU ROGERS, BILL CASWELL AND RON MARSHALL; A CLOSE-UP OF BILL CASWELL'S WORK ON HELEN ROJEK'S COMPUTER EQUIPMENT.

Calgary chapter strikes gold—a rush of new volunteers brings 'energy and enthusiasm'

CALGARY: With a stampede of five new volunteers this past year, it feels like the Calgary chapter has struck gold.

With a relatively new coordinator, Kim Beckers—she's been calling the shots since January 2007—the chapter radiates enthusiasm. Volunteers are finding themselves hanging out after meetings and have even decided to forgo the customary summer break so they can continue to meet all year round.

The most important thing to Beckers, an occupational therapist in a children's hospital, is that there is a good mix of skills and a willingness to share ideas and cross-pollinate.

The newcomers are retired engineer Bill Caswell; Ron Marshall, who has a wealth of shop skills; Canadian Paraplegic Association client services coordinator Nicola Birchall; Brad Clements, a former client; and Art Sanden, who became interested in Tetra after manufacturing items to help a friend who is quadriplegic.

Marshall and Sanden each responded to a classified ad seeking volunteers, while Caswell heard about Tetra through brother-in-law Marvin Pflug, a longtime Vancouver volunteer. Clements came through contact with the chapter, and Birchall is his CPA peer counselor.

"Nicola Birchall and Brad Clements do marketing and keep our feet on the ground," explained Beckers. "They are very good at understanding what clients are asking for, and how simple things can make a big difference to someone's life.

"They do a lot of research for us, and also have an incredible social network to promote Tetra. Right now they are in the process of collating lists of agencies we can send information packages to."

Beckers is quick to point out that the newcomers are working with a core of long-term and very experienced volunteers: Vern Pauls, Stu Rogers and Doug Brown.

Beckers describes the trio as "my rock," when she first became coordinator—and a key component with subsequent success. In addition, there are a couple more volunteers that, for various personal and professional reasons, don't have time to be involved right now.

"Having the five new volunteers has been really good because I'm seeing a lot of collaboration, with volunteers helping each other out," she said. "The new volunteers are bringing new energy and enthusiasm.

"The overall willingness to problem-solve, and consider multiple options, is fantastic."

She has seen the change in the monthly volunteer meetings, held in a grocery store community room. "Meetings are at least two hours now," she continued. "The amount of brainstorming is incredible. There are jokes, and there are still conversations going on afterwards."

There is a purpose to all this, of course. The chapter has completed six projects so far this year, with more interesting ones underway.

One is a lift to enable a quadriplegic man to dress independently (Nicola Birchall and Art Sanden are working on this). Another is a carousel-type device to hold various pieces of equipment next to a quadriplegic's bed, which can be rotated so that the desired item is close at hand (Vern Pauls is working on this); and a third (handled by Bill Caswell and Ron Marshall) will see the creation of a Braille business card printer.

"We are building up a wealth of expertise," said Beckers, "from social networking, through mechanical engineering, to problem solving, research and marketing."

She made an invitation to anyone interested in volunteering to come along to a meeting and talk things through with the group. You can reach Kim Beckers at 403-259-5783 or tetracalg@yahoo.com.

Tetra has more uses than duct tape

CALGARY: Volunteer Bill Caswell grew up on a farm, so manufacturing solutions to mechanical problems is nothing new to him.

The 62-year-old engineer worked as a plant engineer for a variety of natural gas plants and oilfield surface facilities before taking early retirement. A volunteer since last summer, his most notable project was to secure the sip 'n' puff equipment of quadriplegic Helen Rojak, which was forever slipping out of reach.

"She uses her computer a lot, which she controls with sip 'n' puff," explained Caswell. "Her glasses have some sort of dot that enables the computer to track where on the screen she is looking. She moves the cursor with her head, and using sip 'n' puff is like clicking a mouse.

"The system she had was a six-inch ruler, duct taped to something else on her wheelchair arm. The transmitter was sitting on her lap and would slip off every once in a while."

He tethered the sip 'n' puff control and built a rack to house the other equipment. In the process, he added a switch to enable Rojak to reverse her wheelchair by sip 'n' puff, and also created a cup holder from a microphone stand.

His current project, with fellow volunteer Ron Marshall, is a printing press to enable a blind client to continue his business, adding Braille to business cards.

"He has a manual arbor press, which he uses to do thousands of these things. His arm is getting pretty sore. He doesn't mind manually feeding the cards, but wants something air-powered or electrical."

Projects that give new life to children with disabilities

CINCINNATI: Tetra's Cincinnati chapter is specializing in projects that give new opportunities to children with disabilities.

Volunteer Bill Wood detailed their latest project: "We are working on supplying a special desk for a three-year-old youngster with cerebral palsy. We are also furnishing special pants for a young boy, who has no legs and scoots around on his backside.

"He is extremely active and keeps up with his siblings in all activities. He wears through his pants' bottoms about as fast as his family can buy him new ones."

They have tried add-on denim patches and pressure-sensitive adhesive polyethylene patches without success and are currently researching alternatives.

Wood detailed projects completed over the past year:

- Modifying an adult shower wheelchair to fit a seven-year-old boy with cerebral palsy who wanted to shower without the assistance of his caregiver mother.
- Adapting a racing game with foot pedal accelerator and brake controls, to hand operation, for a youngster with cerebral palsy who has no foot motion capabilities.
- Building a work-table for a youngster to drive up to in his manual wheelchair, which could be folded and stashed under a bed when not in use.
- Building a mobile stand to enable a teenage boy to transport his life-support ventilator on the school bus and family vehicles, and a floating support for his ventilator and battery pack so that he can go swimming with his friends. ("The youngster has been tethered to the ventilator all of his life by a four-foot-long tube.")
- Fitting a toddler-size bath to a family's very small bathroom so that the mother, pregnant with her third, wouldn't have to lean into the family tub to bath her five-year-old, who has cerebral palsy.
- Building a trumpet stand for a nine-year-old girl, with one arm and one leg. She plays the piano but needed another challenge in her life.

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Tetra Society of North America

CELEBRATING OUR 20TH ANNIVERSARY

Have an idea for a project? Want to know what's possible? Want to overcome a barrier?

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