



June 2012

# Headwaters Foundation, Inc.

## *Our Ray of Light-Kiran James Bessire*

Having a child changes your life forever- but my husband and I were unprepared for the ways in which our lives would change when our twin boys were born on January 27, 2009.

The pregnancy had gone well, and despite twin gestation, was uncomplicated. When the boys were born via C-section at 37.5 weeks, I felt like I'd beat the odds. I'd carried them full term, with no complications.

Now I could put all of the horror stories of premature births, behind me. I could forget about those chapters in the baby book that I didn't want to read- the ones about complications, especially with multiples. I could brush aside the statement from my doctor who said twins weren't twice the trouble, but six times the trouble. I could turn my thoughts toward loving the two newest members of my family- Skyler L.J. and Kiran James. The boys each seemed to fit the names my husband and I had deliberated over. Skyler was a name we'd considered for some time, and we liked the sound of Kiran- meaning "ray of light" in Sanskrit. Their middle names were taken from my grandfathers. Even though newborns often look like old men, Kiran's resemblance to his namesake, my grandpa Jim, was striking.

Both were beautiful boys with blue eyes and full lips. Skyler, first-born and a bit larger, was fair, with a dusting of blonde hair on his head, while Kiran looked more olive-complected. He had beautiful smooth skin, a delicate face, and soft brown hair. My husband and I joked that Kiran was the new model, since Skyler resembled his older sister, Solenne.

I didn't realize then that while the birth was over, the complications were just beginning. I noticed Kiran's muscle tone was a bit stronger than Skyler's, but didn't think much of it. He was nursing well, and gaining weight like his brother. At three weeks of age the first sign something was awry surfaced- Kiran began lifting his arm away from his body, and jerking it five or six times in a row, exhaling with each jerk. The first time I saw this happen, I thought he might have some kind of involuntary muscle movement problem, like Tourette's. I told my parents about it- I had been staying with them during the last months of my pregnancy since my husband's job had us living out of country. My dad said he thought it looked like a seizure. We immediately called Marshfield Clinic, and made an appointment to have Kiran looked at by a neurologist the following week.

It was a challenge to glue all the little electrical leads for the EEG on the head of a baby as small as Kiran, but the technician managed. The leads had wires coming out of them that fed into a computer to record the electrical activity in Kiran's brain. I held Kiran in my lap, his head resting on a pillow. All of the leads hung down over my arm like a multicolored ponytail. I was given a small button to push if I thought he was having a seizure, which would help the neurologist identify areas of interest in the EEG. We were recorded via video camera throughout the hour we were there.



*One-month-old Kiran in my lap during his first EEG (Electroencephalography) at Marshfield Clinic.*

**established to benefit the participants served by Headwaters, Inc.**

Kiran performed for them- he had a seizure- helping the neurologist to see what we were talking about. After Kiran had been unhooked, and his head rubbed with a stinky solution to try and get the glue out of his hair, we went to meet the doctor in her office.

It was one of many such visits over the next year, in various hospitals, with different accomplished neurologists. Each time I felt like someone was pushing me further underwater. In the first meeting we were told that yes, Kiran was having seizures, and that it wasn't a good sign when babies as young as Kiran demonstrate seizure activity. Seizures could impact Kiran's cognitive ability or development, but there was hope we could control them with medication.

We began our foray into a whole battery of drugs. First we tried Phenobarbital, and when that didn't work, Topomax, Prednisone, the Ketogenic Diet, Ativan and then finally Felbamate and Keppra. Some of these drugs are known for having doping effects, even for adversely affecting the cognitive development they are trying to foster. Some of them are known to cause liver problems. It wasn't what I wanted to be giving my new baby. I had bought BPA-free bottles. I was using cloth diapers and organic baby bath soap. All of my efforts to protect him from unwanted chemicals seemed silly when I was pouring poisons down his throat three times a day, but what choice did I have? I didn't want him to be having seizures either- when he had them they took him over. He became tense throughout his body, and was at their mercy until the seizure ended, when he seemed worn out. Deflated.

The news got worse and worse with each successive doctor consultation. We were told that after trying two drugs without success, epilepsy is considered intractable, or hard to treat. We were told Kiran might be having infantile spasms, a severe form of epilepsy that would make him digress developmentally, and had to be aggressively treated. We were told that he wasn't meeting any milestones, like his brother. We began to realize that Kiran would never smile, sit, crawl, use his hands purposefully, walk or talk.

He wouldn't be able to look us knowingly in the eyes. The knowledge that he was severely disabled began to slowly sink in.

There were a couple of major crises: one medication used to treat Kiran for infantile spasms, called ACTH, made Kiran's blood pressure go through the roof, and he almost died from hypertension. At five months of age, he

had to be put in the pediatric ICU for several days with an IV placed directly into his femoral artery in order to pump medications that could bring the blood pressure down.

When he caught a virus at about 9 months of age, Kiran went in to respiratory distress, and had to be admitted to the ICU for three weeks and put on a ventilator, or breathing machine, to help him recover. He had to be kept sedated to tolerate the tube down his throat. After a few days I asked the nurses if I could hold him- it took two of them about 15 minutes to re-

arrange his cords and tubes so that they could lift him slowly off the bed and put him in my lap. He was all puffy from fluid build up which made the fat folds in his skin even more pronounced. He looked like a stiff little doll-sized sumo wrestler.

When the medications we were trying failed, and Kiran still had no relief from the seizures, we felt desperate, and began searching for someone who could help him

further. At Milwaukee Children's Hospital I met my favorite neurologist, Dr. Mary Zupanc, who had a lot of experience working with children like Kiran. She was brave enough to tell me what she thought was wrong, and what she thought we were facing. Kiran had been through a whole battery of tests, but with nothing conclusive. He had been tested for many genetic diseases, including Retts Syndrome, Fragile X, Tuberous Sclerosis, and various mitochondrial diseases, but nothing came back positive- everything showed up as normal, including his MRI brain scans.

Dr. Zupanc gave us the most devastating news we had heard yet. She told us she thought Kiran had a neurodegenerative disease- one that would get worse over time. She believed he would



*Kiran (bottom) and twin brother Skyler (top) napping together.*



*Kiran in the Pediatric ICU in Marshfield, intubated and sedated. I finally got to hold him with the help of two nurses who adjusted multiple tubes and lines to make it possible to move him out of his bed. He was 9 months old when he had this episode of respiratory distress, and was hospitalized for three weeks, but finally made it off the ventilator.*





*Kiran with his great-grandma Clara in Minnesota at age 18 months.*

slowly lose muscle control, including the muscles regulating breathing, and would live until he was about 2 or 3 years old. She recommended I meet with some palliative care people, who could help my husband and me make decisions about Kiran's care.

Strangely, I felt some relief because of her honesty- someone was finally telling us what they thought we were dealing with, and was willing to hazard a guess about the future. I wasn't ready to believe it yet, but it was important for us to know what might happen. We needed to know the worst-case scenario. We needed to prepare ourselves for what might lie ahead.

Under Dr. Zupanc's care Kiran had several months of relative stability. We saw a dramatic decrease in the seizure activity- her cocktail of Felbamate, Keppra and Ativan was successful, for quite awhile, in eliminating his large seizures. I had some peace knowing we were giving him the

best chance we could. If he could develop or progress, we were giving him the best opportunity to do so.

Unfortunately he didn't develop, and what skills he did have, like drinking from a bottle or tracking light sources with his eyes, he slowly lost. We began feeding him thickened formula or milk or other pureed foods that were easy for him to swallow when runny liquids became too hard for him to handle, causing him to choke. The decline was never drastic; in fact it was so gradual it was easy to believe- to hope- that we could go on and on indefinitely, like he wasn't in imminent danger. We settled into a routine when he was out of the hospital; my mother and I spent time every day holding him, rubbing his back, cuddling.

Kiran went on receiving his physical therapy through Headwaters Birth to Three program to try and keep his joints limber despite disuse. He got a fancy new supportive chair that held him upright in a seated position, aligning his spine properly to minimize the scoliosis he was already developing.

We made plans as to how to move forward with the altered composition of our family. Could we continue my husband's career overseas? Where could we go where Kiran could get the services he needed? When Tel Aviv, Israel became an option, we decided it



*With family:  
Back row, standing, L-R: Kiran's grandpa Bill, and mom Kirsten  
Front row, seated, L-R: Kiran's grandma Carol, twin brother Skyler, sister Solenne, great-grandma Clara, sister Bopha, and dad, Bradley holding Kiran in Pelican Rapids, MN.*

*Kiran at Christmas time, almost one-year-old, with grandma Emily and grandpa Joe plus siblings Solenne, Bopha and Skyler.  
Photo credit: Kitty Sookochoff of Lakeside Photography in Eagle River. Kitty provided us with beautiful photos of Kiran- thank you!*



would be possible to move. Israel is known to have excellent medical care. We wanted to be together as a family again (my husband had been in Afghanistan since the boys were 5 months old) so we researched and were happy with the medical services we found.

Once in Israel, we discovered a great center for Kiran to get physical therapy, hydrotherapy and even tickle therapy for free, since we qualified for the state benefit. We were so excited! We met experienced and thoughtful neurologists to help us. Israel was a good choice for us, and we were settling in...

While we were trying our best to make Kiran comfortable, his disease was doing the opposite. It continued to progress, and I noticed he had more and more trouble swallowing his medications and handling his own saliva, choking on both. At times his breathing was labored. After a few months in Israel another virus sent Kiran into an episode of respiratory distress that he could not recover from. He died two months shy of his

second birthday, on November 17, 2010 after two days at the Dana Children's Hospital in Tel Aviv.

There was an incredible amount of pain, stress and grief in those nearly two years. There still is a lot of pain and grief, but despite the trauma of the situation, there was, and still is, so much love. Love for a very special little boy who liked nothing better than to be held and cuddled. Love and support from grandparents for him and for us. We let Kiran know he was loved-throughout all of the hospitalizations and demands placed upon us, he was surrounded by people who cared for him: his parents, sisters, brother, grandparents, aunts and uncles, cousins, babysitters and friends.

We set up the Kiran James Bessire Memorial Fund at Headwaters on the one-year anniversary of Kiran's death. We want to continue to remember him, but also to provide support for people with disabilities and their families. If it hadn't been for helpful services from Headwaters and other organizations that worked with us, I think the stress of the situation would have been overwhelming. It was important for us to know that others had been through similar challenges to ours, and that there were places we could turn to for help and guidance.

Kiran's fund will not only memorialize our little boy, but also support an organization that has done so much to meet the needs of families and individuals with special needs in the Northwoods. We have been so changed by our experience that we now feel driven to affect change for others. We want Kiran's name to live on, and his life to continue to touch the lives of others.

Thank you to all who have contributed to Kiran's fund, and thank you to Headwaters for helping us find the right way to remember our little ray of light. We love you, Kiran!

- Kirsten Bodensteiner



*Kiran at home in Tel Aviv, around 21 months.*

# HEADWATERS FOUNDATION



# Twenty-seventh

## ANNUAL GOLF TOURNAMENT

### Monday, August 13, 2012

### *Save this Date!!*

Shot Gun starts at 8:00 a.m. & 1:00 p.m. at the Rhinelander Country Club. Tee, Door & Flight awards. SCRAMBLE - 4 Person - Shot Gun Start. Entry Fee \$95 Per Person. Includes golf, carts, prizes & dinner. Raffles and Auction following dinner. For more information, call Jon Konz at 715.365.3201





## Foundation President's Report



The Headwaters Birth to Three program provides help to those families who are coping with special needs infants.

Although there are various government agencies that provide assistance, there are also needs that are not covered. In nearly all of these cases the child is kept at

home and the mother becomes the primary care-giver, sometimes on a 24/7 basis. Just imagine the challenges these mothers face every day.

Thanks to generous contributions by Joe and Emily Bodensteiner, their family and friends, we have established the Kiran James Bessire Memorial Fund. All monies in this fund will be directed to our Birth to Three families.

Based on our Service Coordinators recommendations we can now offer help to these families. It may be a relatively small item, or in some cases it may be more expensive, such as providing licensed nursing care that can give the family a break from their routine.

If you would like to contribute to this fund, please make your check payable to Headwaters Foundation with a note to direct the money to our Birth to Three program.

*Dennis Herrmann*

President  
Headwaters Foundation, Inc.



## Headwaters Foundation

*Incorporated in 1985, the Headwaters Foundation is a tax exempt 501(c)(3) private foundation whose sole mission is to provide financial support to benefit the programs of Headwaters, Inc.*

*Gifts to the Foundation ensure that Headwaters will always remain a viable service for the many individuals with disabilities who come for services from throughout Forest, Oneida, and Vilas Counties.*

*The Headwaters Foundation allows individuals the opportunity to make lasting tributes to benefit others, offering a wonderful way to affirm supporters' values and priorities. Honoring loved ones through charitable giving is often an especially meaningful act of paying tribute to someone special.*

## Headwaters Foundation, Inc. Legacy Society

An opportunity to continue supporting the work of **Headwaters** is extended to individuals by inviting you to become a member of the **"Legacy Society" of the Headwaters Foundation, Inc.**

### Legacy Society Named Funds

A Named Fund is a contribution or group of contributions that total a minimum of \$5,000 or more given in the name of a person, foundation, business or organization. When gifts made to a Named Fund do not yet total \$5,000, it is referred to as a Named Fund in Process. When cumulative gifts exceed \$5,000, it is referred to as a Named Fund Established.

A Named Fund may be added to at any time and grow to any amount. Named Funds will be recognized on the Honor Wall located in the entrance at Headwaters, Inc.

### Named Funds

Kiran James Bessire Memorial Fund

Elmyra Hobbs

LaSalle St. Securities, LLC

Andrew, Lisa & Lace Loduha

(In Memory of Gary C. Loduha)

M&I, a part of BMO Financial Group - Rhinelander

M&I, a part of BMO Financial Group - Eagle River

John & Kathy Powers

Lon, Ginny & Sheila Sherman

Dr. Martin & Kathryn Smith

### Named Funds in Progress

Mary & Ken Hardtke

Barbara Sironen - In Memory of Eric Gavin Amaral

Knights of Columbus-Father Dodge Council 7827, Woodruff

For additional information please call:  
**Mary Hardtke, Director Headwaters, Inc.**  
**1441 E. Timber Drive • P.O. Box 618**  
**Rhinelander, WI 54501-0618**  
**715.369.1337**

**New in 2011 - Donations may be made  
through our website  
[www.headwatersinc.org](http://www.headwatersinc.org)**

*HEADWATERS offers VALUE...  
for the individuals served through  
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community itself.*

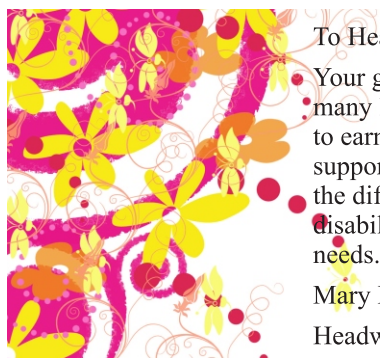
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## Headwaters Foundation, Inc.

*When you give a gift to Headwaters in your will, you leave a legacy that will last and grow. A gift to Headwaters will make your resources count for years to come. By designating Headwaters in your will or insurance policy, you help guarantee a positive future for people with disabilities. Your gift will continue the important work that you, as a supporter started...your gift will leave a legacy for the future.*



To Headwater's Supporters:

Your generosity has a way of touching many lives. Headwaters will strive hard to earn your continued respect and support. It is people like you who make the difference in the lives of people with disabilities and children with special needs.

Mary Hardtke, Director  
Headwaters, Inc.

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