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Showing Support through Team Alexis

Childhood cancer research is crucial.

BY DELIA SAVA
THE CONNECTION

It was devastating news for Jonathan and Neely Agin. The parents of then 2-year-old Alexis were told on April 10, 2008 that Alexis had DIPG (Diffuse intrinsic Pontine Glioma), a form of pediatric brain cancer.

"The diagnosis was bad enough but then when we're told that there really aren't any treatments that have any efficacy behind them," said Jonathan Agin adding, "The statistics vary but roughly 95 percent of children diagnosed with DIPG make it 9 to 12 months after diagnosis so it's a very short prognosis and Alexis is considered one of the longer-term survivors."

Agin explained that the main symptom that prompted them to take Alexis to the doctor was that her right eye was inverting or turning inward periodically. Her pediatrician recommended that Alexis have a CAT Scan. "That's when the mass showed up on the scan and they immediately admitted her and she spent two days in the hospital [Inova Hospital] and they did an MRI to confirm the diagnosis," said Agin.

Marainna Horn, M.D. told the Agins the diagnosis; she has been Alexis' primary pediatric oncologist for the past 31 months. "Within the types of brain tumors that occur, DIPG is the most challenging of all, in that it has a terrible prognosis," said Horn adding, "We really need to just get more research done in order to help those children."

Horn, who is with Children's National Medical Center in Northern Virginia, is the medical director of the Center for Cancer and Blood Disorders. She noted that in addition to more research, improvements need to be made "within the pediatric realm" to support families and provide services. "Even things like hospice programs are not well-delivered or well-staffed or even as available for pediatric patients as they are for adults," she said.

Two years ago the couple became involved with The Cure Starts Now, a



Neely and Jonathan Agin holding Alexis.

PHOTO BY DELIA SAVA/THE CONNECTION

501(c)(3) non-profit organization established by Brooke and Keith Desserich, after the loss of their daughter to brain cancer. Agin stressed that in more than 30 years there have been no advancements in treatments and money to fund research is critical.

"Their singular goal was to raise as much money for research as possible and that aligned with our goals," said Agin adding, "so we formed the Washington D.C. chapter which we call Team Alexis." Agin who has been running for about 10 years, came up with the idea for a race to raise funds for pediatric brain research. "It was a natural outlet — running has been a huge catharsis throughout the entire 31 months of this ordeal and in trying to raise awareness and money to fund research and fund protocols, it seemed like a natural fit."

Tom Martin, a retired Arlington resident who had coached Agin to run in marathons stepped in as race director in June of last year. Martin had no experience organizing an event of this magnitude when he got involved. "In 3 and a half months of planning we built a race that was a class event — we had 600 registered runners and raised over \$60,000," said Martin.

The National Race Against the Odds, a Team Alexis 5k for pediatric brain cancer research, was held on Nov. 7 at Bluemont Park in Arlington. Martin said it has been important for him to do whatever he could to "take the load off of Jon and Neely so they could spend as much time with Alexis as they could."

BOTH MEN in separate interviews expressed their gratitude for the team of people who helped with the race and the overwhelming support from the community. According to Agin, this year's race drew 751 runners, 136 children for the Fun Run and 35 corporate sponsors, including premier sponsor Brandywine Realty Trust. Final numbers have not been tabulated but Agin expects this year's total will be more than \$80,000.

Cancer is the number one disease killer of children in America and brain tumors are the second most common cancer in children, according to Agin who wants to see a bill passed by Congress to allocate funding from the NIH to study the cause of childhood brain cancer.

Agin also believes that changes should be made to lessen the emotional and financial burdens faced by parents of seriously ill children. Navigating the health care system can be needlessly difficult and frustrating, including participation in clinical trials where families have to travel at their own expense.

Alexis participated in a clinical trial at Sloan-Kettering Cancer Center in New York City but treatment had to be stopped. "During the course of the trial she showed a benefit but she had an acute bleed that occurred inside the tumor."

At this time Alexis is at home on hospice care. Agin said they have been told that there's nothing more that can be done in terms of intervention because of the location of the tumor.

The couple has established a site where family, friends and supporters can stay in touch: www.caringbridge.org/visit/teamalexis. Being able to share this painful experience with others on the blog has been a catharsis for them. They also have a 22-month-old son, Gabriel. To date Agin said the site has received more than 560,000 hits.

"Our entire goal is to first off save our daughter — to try to do anything and everything possible to find a treatment, to find a cure, it's a completely selfish endeavor," Agin said adding, "Neely and I have tried to open ourselves up to other families to provide information and support and there's a lot of people in the community who do that."



PHOTOS BY LOUISE KRAFFT/THE CONNECTION

Arlington County Board Chair Barbara Favola congratulates Fr. Gerry Creedon on being selected for the award.

Creedon Receives Bozman Award

Father Gerry Creedon received the Ellen M. Bozman Award for advancing affordable housing in Arlington on Saturday evening at St. Charles Borromeo. The award was inaugurated in 2009 by the Alliance for Housing Solutions, in memory of Bozman, a longtime Arlington county board member (1974-1997) and chair, supporter of affordable housing, and a founder of AHS.

Creedon co-founded Catholics for Housing which since 1979 has provided home ownership initiatives, affordable rental housing, senior housing rental assistance subsidies, security deposit assistance loans, public education and advocacy. In 1982 he co-founded Gabriel Homes providing residential housing for developmentally-disabled adults: the first house was established in 1985; today there are seven residential facilities that also provide life skills for independent living. He was instrumental in revitalizing Good Shepherd Housing which used Section 8 vouchers to secure housing opportunities. During his tenure as director of Catholic Charities, he expanded Christ House homeless shelter services. Over his 14 years as pastor of St. Charles, he was a steadfast supporter of Borromeo Housing, Inc. which provides housing and "new start" opportunities for homeless mothers and their infants.

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Be a Part of CHILDREN'S (& TEENS') CONNECTION

Every year between Christmas and New Year's, The Arlington Connection turns its pages over to the contributions of local students. We are seeking artwork, photography, poetry, opinions, short stories and reflections. We welcome contributions from public schools, private schools and students who are home schooled.

E-mail to: arlington@connectionnewspapers.com, or mail (.jpg and text files on disc only) by Dec. 1, to 1606 King St., Alexandria, VA 22314. Please be sure to include the student's name, age, grade, school and town of residence along with each submission. For information, call 703-778-9410.

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