NOAH Fundraising, Fun, and News

Spring into Action! That's How NOAH Rolls!

By Joni Vella

2019 marks the fourteenth year of NOAH's grassroots spring fundraising efforts. Members across the country plan and attend events and seek donations to help raise vital funds to keep NOAH moving forward.



NOAH has raised 80% of our \$150,000 goal so far. From the longest running NOAH bowl-a-thon in Northern Illinois, to brand new events in Southern California and Staten Island, there are plenty of opportunities to support NOAH.

While these events are fundraisers, they are so much more! They are an opportunity to connect with others with albinism and their families locally, to share information and resources with one another, form friendships, and just have fun. Albinism awareness is happening without any extra effort. People with albinism are being seen doing normal, everyday activities, having fun and enjoying life. Education



happens informally. There are plenty of opportunities to answer the questions of your friends and family who have come out to support you, whether by talking with them or creating posters or information displays.

The variety of events this year is astounding. Ranging from traditional bowling events to pool parties, a Disney scavenger hunt, music and comedy shows, and a golf tournament, the possibilities are endless. Some events have spilled over from spring to cover the entire calendar year. There is no right event or right time to get involved!

The comments and pictures from the events that have already been held say it all. They show just how much the need for community is for those with albinism and their families. The pictures of kids who might become lifelong friends. The family that is attending their first NOAH event and meeting another person with albinism for the first time. The parent liaison who gets to meet three of the families that she helped when they first received their diagnosis. You can't put a price on these experiences.

NOAH have raised over two-thirds of our \$150,000 goal so far. With the support of the entire NOAH community, we can easily surpass this goal.

Here's a huge THANK YOU to all of our event hosts. You make a difference. You are amazing!

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Starting Small, Growing Each Year

By Regan Gentile

This year, my husband and I hosted our third annual fundraising event, 'This One Is For Elise!' It is so hard to believe this was our third year as it feels like yesterday that we were trying to determine a new and fun way to raise money for NOAH. Originally, we wanted to start small without a lot of pressure. I and my good friend Courtney, a stylist for Stella & Dot jewelry, thought it would be fun to have a sip and shop event. What could be more fun than having a girls night and shopping while raising money for NOAH?

The evening was such a success that we did it again the second year, adding a craft beer element to widen the guest list. While it seemed intimidating to start planning a fundraiser, we found that starting small and with something you are passionate about is the key to a fun and successful event. As each year passes, our guest list grows and we continue to raise albinism awareness in our community.

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This year, our event surpassed our goal for a total of \$2,870! Our goal for next year is to build upon what we have done in the past while reaching new members of the NOAH community and our neighbors!





Dallas Bowls for NOAH

By the Leavell and Widell Families

Thank you to everyone who came out and made our second "Dallas Bowls for NOAH" a huge success! With over 150 people in attendance, we had a ton of fun and surpassed our fundraising goal. We felt especially blessed to have NOAH Executive Director Mike McGowan come to town and speak. We loved getting to meet other NOAH members in our area and look forward to meeting even more next year!



CJ's Crew By Christen DiGuglielmo

The CJ's Crew bowl-a-thon on May 4th at Holiday Bowl in Oakland, NJ was a huge success! Thank you to so many amazing people for coming out to bowl and show your support to the albinism community. Thanks to the generous support of our family and friends, we raised over \$6,900 for NOAH and had over 75 people attend!

We welcomed the Girl Scouts of America Willard Daisy Troop 97740 to help at our fundraiser. The Daisy troop earned the "Daisy Good Neighbor Badge" for assisting the children bowling and selling tickets for our raffle baskets. We're looking forward to next year's event!



White Cheddar – Milwaukee

By Gacia Coronado

Our first NOAH bowl-a-thon was an experience I would repeat over and over. With an infant with albinism, we are new to this community and have so many questions! What can he do with his vision? Will other kids pick on him? What should we do as parents to help him thrive?

This bowl-a-thon was a safe place to ask those questions and more. We were overwhelmed with kindness, gentleness, and a sense of belonging. It was the first time we weren't the "experts" in the room, and that was so liberating.

This was also a chance for us to look into the future. What does life look like for a fouryear-old? Or eight-year-old? Or an adult with albinism? Well... it looks normal. This isn't to say there are no challenges ahead for our little Matias, but I do feel comforted. All of these wonderful people have been in our shoes or our son's.



The 2019 St. Louis Superstars

Adam, Braxton, Jocelyn, Liam, Nikki, Oliver, Rocco, and Rowdy– had an amazing NOAH bowl-a-thon on Sunday, April 7th with an estimated 170 participants. This was our seventh annual fundraising event for NOAH.

We had an incredible selection of donated silent auction items to bid on, including Cardinals baseball tickets, wine, beer, gardening baskets, a train set, and gorgeous jewelry. In addition, there was a 50/50 raffle where the winner generously donated back the entire

Thanks to our planning committee and very generous donors, sponsors, families, and friends, with donations still coming in, St. Louis raised more than \$19,000!

amount!







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Shout Out to NOAH's Amazing

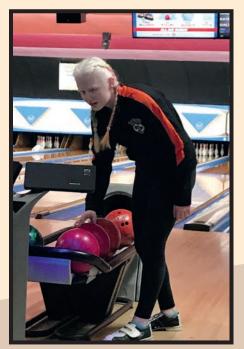


















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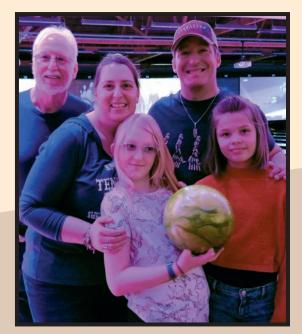
Bowl-a-thon & Spring Fundraiser Hosts!



















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Albinism InSight, Summer 2019

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North Carolina By Brendan Rodden

The 2019 NOAH bowl-a-thon for the North Carolinas in Chapel Hill was a great success for the third year in a row. Several NOAH families and friends attended the event to raise money and

awareness of NOAH for the local community and for those with albinism. We welcomed a new NOAH family with a newborn with albinism.

One of the sponsors for the event was low vision company Ocutech located in Chapel Hill, North Carolina. Ocutech is probably very familiar to many NOAH members for their bioptic low vision aids and other devices used by people with



different vision impairments. Ocutech employees bowled with us and demonstrated their low vision aids.

Next year will be even bigger and better for the North Carolinians, and hopefully we will see more new faces.

Bowl for Albinism with the Rogers

We, the Rogers family, have been hosting a bowl-athon for many years since our oldest child, Ashleigh, was born with albinism and became involved with NOAH. This year we had eighteen attendees. We will continue to host our annual event (no matter how large or small) as long as we are able!





We had three families with children with albinism this year, and the largest group of children total for all the events we've hosted thus far. Good chats and fellowship were had regarding care and support for our amazing children amidst the clamor of falling pins.



Bonus: More Fundraising Fun in the Carolinas!

Carolina Cannonballers had a great day of water fun and fundraising! Families from across South Carolina and North Carolina attended, including nine people with albinism. The kids enjoyed a water fight, sidewalk chalk, and bubbles. We were grateful for amazing donations including food from a local pizza restaurant, sweet treats from a local bakery, and lots of sunprotective clothing from Coolibar! We can't wait to get together again soon!

