



photo courtesy of Rick Guidotti

A Tribute to Mike McGowan

On November 24, 2024, the albinism community was shaken by the passing of NOAH's former Executive Director, Michael McGowan. As we honor Mike's remarkable legacy and reflect on his profound impact, we are reminded of the strength of his vision, the depth of his dedication, and the kindness with which he led.

Mike was a pillar of strength and an unwavering champion, dedicating more than three decades to advancing the rights, awareness, and support of individuals with albinism and their families.

NOAH will continue to honor Mike's memory as we strive to build a world of understanding, empowerment, and equality, providing the resources and opportunities necessary for individuals with albinism to thrive.

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Kathi Garza writes,

I feel truly humbled to have had the pleasure to know and collaborate with Mike McGowan through NOAH. For me, what was more profound was the development of a friendship and Mike's impact on my own personal growth as a volunteer and person with albinism. His gentle smile and manner of speaking was incredibly welcoming, and his support of my involvement in NOAH from the very beginning was paramount to my developing self-worth. Mike was always eager to hear my perspective or ideas for articles, conferences, and webinars, and I enjoyed every minute of the "quick debrief" conversations after conferences or adult events that turned into two or more hours on the phone together. Every idea I had was welcome, and he was always available if I got stuck or needed a little push. That being said, he was patient when things didn't happen within the timelines I originally anticipated. The trust he put in me to see things through made me feel empowered and capable

in ways I never had before. I was honored when he attended our mini-conference in Austin in 2015 and even more thrilled when he asked me to take on programming responsibilities at NOAHCon.

Mike was one of the first people I connected with through NOAH, and he immediately felt like family. I knew he felt the same when he began to refer to me as "little sis." I strived to create moments to bring out that infectious laugh he had, and I will never forget the sound of his voice greeting me with a jovial, "Hey Kath-I," whether it was over the phone or upon meeting at a NOAH event.

His memory will continue to occupy a special place in my heart, and I extend my deepest hope for comfort for everyone impacted by this great loss.

Antoine Gliksohn, Executive Director of the Global Albinism Alliance, writes,

Mike and I first met in August 2011 during an online meeting organized by the Albinism Fellowship of Australia. The goal was to foster international collaboration among albinism organizations worldwide. At the time, Mike was the NOAH Board



Photo from Antoine Gliksohn

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President, while I was a newly elected board member of Genespoir, the French albinism association. I was just beginning my journey as an advocate.

The only clear memory I have of that first encounter was the impression of facing yet another arrogant American—someone who knew little about the rest of the world but was certain that the U.S. was the best and most advanced country in every field. I had the impression that he didn't expect NOAH to gain much from other albinism groups, but rather believed it had only experience and resources to offer them.

After this first meeting, we would call each other on Skype or exchange emails every once in a while with no particular goal other than getting to know each other better. Despite my initial, rather negative impression, it quickly became clear that I was fascinated by Mike. The depth of his knowledge and experience was remarkable!

I finally met Mike in person in March 2018 at a European albinism conference in Norway. Despite the harsh

winter, Mike had traveled all the way from Chicago at his own expense to spend a few days with European albinism group leaders, who were struggling to find a way to collaborate. That's when I realized how open-minded, modest, curious, and eager to learn Mike truly was—a man who had always lived within Chicago's city limits, as he often liked to mention.

The meeting in Norway paved the way to what soon became our joint project: the crazy idea to unite albinism organizations globally! Guided by the leadership of the former UN Independent Expert on Albinism, IK Ero, we turned this idea into reality during an exploratory

meeting that the three of us organized in Paris at the end of January 2020. Joined by 27 albinism organization leaders from all regions of the world, we officially created the Global Albinism Alliance.

Mike and I then slowly but surely became real partners in crime. After he left NOAH in September 2020, our collaboration became even stronger. We would spend hours on Zoom strategizing and discussing what the mission of this organization could be and how to best develop the GAA.

Mike was driven by passion and a strong desire to do things well. His experience and expertise helped us



Photo from Antoine Gliksohn

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solve numerous problems and navigate dead ends. But what truly made him an outstanding and unique leader, in my eyes, was his genuine commitment to serving the community. He never sought personal gain, he disliked politics, and he always made decisions with the community's best interests in mind. Whenever he was pushed into the spotlight and praised for his work, he did his best to stay in the background.

Mike was my closest colleague and will always be a role model to me. But above all, he was a truly special friend, and I will miss him deeply.

Joe, Sheila, Joey, Angela, Vinny, and Sarafina Adamo write,

The Adamo family has been blessed with knowing Mike for the last 27 years. He was a mentor, counselor, educator, comedian, motivator, and most of all, a friend. He celebrated our successes with us and he held our hand during more turbulent times. Mike's passion for supporting the albinism community will live on in all of us. Thank you for

sharing so much of yourself with us.

Joni Flynn Vella writes, Mike's passion for the albinism community was unwavering. He found and nurtured leadership and fundraising abilities in me that I didn't know existed. I miss working with him on the bowlathon, adult weekend, and other projects. The Parenting Without Pigment sessions and group came about because of an idea I had and he asked me what I thought it should look like and who the target audience was. This picture from Wisconsin's 2019 bowl-a-thon is perfect— the laughter is genuine, because of a 'family picture' comment. You PWAs will understand!

Donna Appell, RN, Executive Director of the HPS Network, writes,

On behalf of the HPS Network, we would like to remember Mike, a leader in advocacy and a dear friend of our organization. Throughout his career, he stood by us with kindness, ensuring that we were never left behind. His dedication was more than professional—

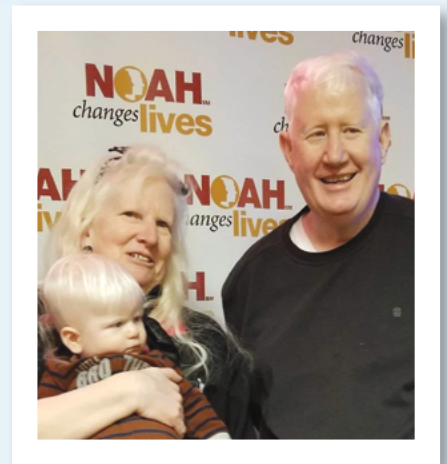


Photo from Joni Flynn Vella

it was personal. He cared deeply about our mission and the people behind it, offering his support with genuine concern.

Those who had the privilege of knowing him have countless cherished memories. Carmen fondly recalls, "I love that he called me his 'booth babe' anytime we had an exhibit! And the fact that he sat with the delegates from South America, giving them advice and asking questions to know more about their concerns! They all admired him so much, as did I. I hope he knew how much respect and affirmation I had for him."

Heather shared, "I always appreciated that he made the effort to come to our conference and spend time

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with the HPS community."

Nancy reflected on their special connection, "I just always felt a special bond. In a sea of albinism, we always managed to find each other. He never missed an opportunity to get together if we were at meetings in my neck of the woods. He was like a brother to me."

His legacy is one of advocacy, friendship, and support. He touched lives in ways that will never be forgotten, and his impact will continue to inspire us. While we mourn his passing, we celebrate the incredible difference he made and the lasting imprint he left on our hearts.

Edward Dalton writes,

Mike tended to have somewhat of a low, quiet voice which made it so much greater when he would absolutely erupt with boisterous laughter. In my years of working with Mike, I asked him to do lots of completely ridiculous things. He agreed to do all of them for the sake of NOAH. Some of my fondest memories of Mike were the "Conference Postmortems" we'd have after the



Photo from HPS Network

conclusion of a NOAHCon with my sister, Kelsey. We'd swap stories about all the funny, perplexing, and outrageous things we'd each experienced. We'd share a lot of laughs and a few pints, but Mike was always looking forward. What worked? What didn't? Why not? Should we scrap an idea or try it from another angle? He constantly wanted to make NOAH better. Under his watch, NOAH became something I struggle to describe to people on the outside. I'll always be grateful for having Mike as a friend and for everything he did for all of us.

The Guskeys write,

Mike's smiling face and radiant personality will live in my heart forever. The impact that Mike had on my family is beyond anything I can put



Photo from HPS Network

into words. At a time when we felt lonely and a bit scared of what the future would hold for our son, Mikey, we were lucky enough to find Mike. A friend told him about us and Mike called right away to offer support and welcome us to NOAH. I realize now how busy he must have been, as he was still employed and already president of NOAH. Yet he always made us feel like he had all the time in the world to chat and make sure we understood that Mikey was going to be just fine. Thank you, Mike! The impact you had in the albinism community will be felt for generations to come.

Regan Gentile writes,

Mike McGowan was instrumental in bringing people together from the

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Northern Illinois community. He inspired and motivated everyone around him and was always the face of NOAH. Mike was always so involved in supporting bowl-a-thons. He never turned down an opportunity to connect and network with other families.

Here is Mike at a NI NOAH pool party. He was always interested in learning about and discussing new technologies and devices.

The Ostroves write,

Mike was always so kind and welcoming and he knew just how to make people feel special. We remember the first time he called our house to ask for help with a NOAH task—it felt like a celebrity was calling! Was this really THE Mike McGowan?!? Calling our house?!? How lucky were we!

Charla McMillan Lowery writes,

I remember talking to Mike after he was voted in as the next President and Chairman of the Board of Directors after me. He said, "I don't have the same vision for NOAH as you do." I said, "You will develop your own vision for NOAH."



Photo from Regan Gentile



Photo from Regan Gentile



Photo from Regan Gentile

Well, he did just that. His vision for NOAH was very progressive and expansive. I believe he fulfilled his vision and took NOAH beyond my vision. He was a great President and Chairman of the Board, as well as CEO. Thanks to Mike, NOAH is where it is today: bigger and better! Thanks Mike!

Brendan Cosgrove writes,

Mike always made you feel like you and your thoughts mattered—be you a naive

college student in over your head or an adult struggling to figure out your current relationship with NOAH.

As a leader, Mike is on a short list of guys I know who I try to emulate in my own professional role. He led by example with humility and humor, sometimes self-deprecating.

I will very much miss the laughs over tasty beverages

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and, as a Cleveland baseball fan, razzing him about the Chicago White Sox. I know that he is most certainly in a good place.

Erin Carrington writes,

Mike and the NOAH Board traveled to the Philadelphia area in April 2019 and joined our family and friends in our annual bowl-a-thon. This is a picture of Mike, the board, my son Danny and friends who joined us that day.

Sue Dalton writes,

About a week after the first NOAH National Conference hosted by our Northern Illinois group in 1992, I got a phone call from a man with a heavy Chicago south side accent. He said he had seen an article in the Chicago Sun Times about our conference in Schaumburg. This man in his thirties, from a large Irish family in Chicago had never had encounters with other people with albinism. He wasn't sure how he felt about the thought of seeing hundreds of people with the condition in one place.

Within a few months, an adult gathering was planned for downtown Chicago, so I gave him the information, and



Photo from Erin Carrington

there he was at his first NOAH event! From that moment on, he took on his mission to get the word out about albinism and do something about it.

Mike initiated the first Northern Illinois NOAH Gala nearly 30 years ago in 1995. He wanted to come up with a way to raise more money to go toward outreach, education, and other needs of NOAH. The gala generated a substantial amount of money, and even better—it was a super fun social event. Of course, Mike said, "Let's do it again!" Since 1995 our Illinois group has raised hundreds of thousands of dollars to go towards NOAH's efforts.

I will miss his smile, his laugh, and his friendship. He has meant so much to my entire family. We have definitely lost one of ours.

Marty O'Connor writes,

I met Mike at the 1998



Photo from Marty O'Connor

NOAH conference in Arlington Heights. My son had not yet turned one year old and our family still had more questions than answers. Meeting Mike changed everything for me. One of the first things he said to me: "Your son will probably not be able to hit a 100 MPH fastball, but most everything else will be pretty much on the table for him!" Mike's words carried weight; he was engaging, energetic, and empathetic—simply put, he was a very good man. Over the years, I travelled with Mike (and often Dan Lee) to numerous Lions Club dinners to ask for support for NOAH. Mike was such a great advocate for NOAH. His passion and his service to the albinism community cannot be overstated.

Here I am with Mike at the Adamo Bowl-a-thon. Rest in peace Mike!

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Rick Thompson writes,

We are all better people for having known Mike. I was on the board of directors with Mike and he taught me (us) how a meeting should be run. Great job Mike. We will miss you.



Photo from Jennie Esposito Jaidinger

Jennie Esposito Jaidinger

writes, Mike was a great guy and very welcoming and friendly. He will be missed!

Lee Laughlin writes,

I first met Mike in 1993 when he dropped by a NOAH Adult Day event for a few minutes to “check things out.” He couldn’t stay, he had other commitments. Many hours and several phone calls to his ride (a.k.a. his wife) later, he finally parted ways with our group.

Mike meant so much to so many, but for me

personally he was the big brother I never had. We’d talk for hours about baseball, politics, Jesuit Education, NOAH, and challenging family members. We were almost exactly 10 years apart in age, so our lived experiences weren’t exactly the same, but we could easily relate to each other. He had a great sense of humor and was always up for a challenge. He was an honorary uncle to my kids. Early on, Tim & I were still heavily involved with NOAH and frequently traveled to Board meetings and conferences with the kids. My daughter Alix would ask, “Are we going to see Hotel Mike?” because that was usually where she got to hang out with him.

Family was so important to Mike. He doted on his wife Sherry and was so proud of his son Bobby. He adored his nieces and nephews and the feeling was mutual. Numerous members of clan McGowan volunteered their time or financially supported NOAH. At the funeral, Mike’s brother Tom summed it up best in his eulogy, “Mike woke up every day wondering how he could make the world better for

other people.” He wasn’t a saint; he was stubborn, and he had a temper. He would do for others to his own detriment sometimes. He loved hard, and lived his life in service to others. Not only through NOAH, but via the Cook County Circuit Court, his local Ronald McDonald House, his local food pantry, and most recently through the Global Albinism Alliance.

My life is exponentially better for having had Michael J. McGowan in it. Rest in Peace my friend.

Elizabeth Drury writes, Mike, M&Ms, and the NOAH Magic

Every time I see the cheerful yellow packaging of classic Peanut M&Ms, I think of Mike and smile. We had quite the M&M tradition.

Before I attended even one official board meeting, Mike had already succeeded in persuading me to accept responsibility for the annual grassroots fundraising effort that we used to call the Bowl-a-thon (now Spring for NOAH). Despite my doubts, resistance, and lack of experience with NOAH fundraisers, Mike sweet-

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talked me into it, assuring me that he would be actively supportive and helpful--and he was! For the next four years, we worked together closely (often with the unflagging Joni Vella), always pushing our goals further than the year before. And we had a running bet: that if we exceeded our goal, he would buy me a glorious, giant package of Peanut M&Ms, but if we fell short, I would have to buy him Peanut-Butter M&Ms, a variety that I mocked as a violation of everything decent in the world of snacks. I snapped a few M&M selfies from time to time just to taunt him about our deal.

We always met and exceeded our goal, thanks to Mike's unmistakable hustle and optimism (and my revulsion at his M&M preference). Needless to say, Mike set the pace. His delight in the contest was so winsome and welcoming that I never wanted to let him down. He was a fun team player, a warm encourager, and a driven leader who set the example, giving generously of his time and hard work, and I am extremely thankful--both



Photo from Elizabeth Drury

personally and on NOAH's behalf--to have had the opportunity to know him and to serve with him.

Scott Gibson writes,

Back in the early days of my being involved with NOAH, I visited Chicago only to find that my friend could no longer host me. Mike welcomed me to his home at the last minute. At one point later on, Mike called me and said, Hey Scott, I have an idea. Me being willing to help out, I said, Okay, what is it? He informed me that he thought we should have a mascot at the Vegas conference named Lucky T Duck. I said, That sounds like a great idea, we haven't done this before. He said, Great, so you'll do it!

Over the years Mike and I had other adventures. Mike

had a great outlook on life and how to make it better for others as well as himself. He was able to touch the hearts and souls of so many. We all have great memories with Mike.

Kelsey Thompson writes,

In the summer of 1993, Mike attended his first NOAH event, and that's when I met him. I was 13. In the years that followed, Mike became a mentor, a role model, a co-star and a dear, trusted friend.

Mike always made me feel like my voice mattered and that I was deserving of a seat at the table, even when I was just a naive kid attending Board meetings with my mom. From Mike, I learned what it means to lead with integrity, humility, and humor.

His work ethic was nothing short of amazing. He genuinely cared so much and worked tirelessly on behalf of people with albinism. He made this world a better place for all of us.

Perhaps one of Mike's most admirable qualities was his vision--and yes, he would have laughed in hearing me make this pun. He possessed

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Photo from Bunkers Bowlers (2014)

the ability to dream big and constantly ask, "What more can we do?" It is with this spirit that he led NOAH and built the organization into a thriving, professionally run non-profit fully capable of meeting the needs of the albinism community.

It's hard to believe I'll never receive another email with an intriguing subject line like, "A few random questions," or, "A crazy idea." I hope he knows the impact his life had. It mattered so much to so many people like me.

Tia Bellm writes,

I had the privilege of speaking with Mike a few times and just in our brief conversations his passion for the organization and compassion for others shined.



Photo from Bunkers Bowlers (2014)

Patricia Thomas writes,

I discovered NOAH in 2007 while researching albinism. I was introduced to Mike when I attended my first conference in 2008 with a newly adopted child, who happened to have albinism. The friendship and knowledge Mike offered was invaluable. NOAH became a mainstay in our family for, wow, coming up on 20 years! Before I knew it, Mike had "encouraged" me to become involved in NOAH programs.

Mike, I was constantly in awe of your seemingly tireless devotion to NOAH as well as your dedication to the global albinism community. Your sense of humor, willingness to join in the fun—climbing through hula hoops at

camp and fencing (yes, Mike, I am planning on giving swords to "blind" kids)—the ability to joke and poke fun at yourself, and your leadership and tenacity are greatly appreciated and will be missed. I appreciate the opportunity to have worked with you over the years and am in your debt for the numerous insights you offered on raising my child. You were right, the goal of raising a child is to come out the other side with a responsible, independent adult.



Photo from Ryan Huizdos

Ryan Huizdos writes,

So incredibly sad. Growing up, I looked up to Mike as such a great role model and wanted to be a leader like he was. His impact on the albinism community

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was immeasurable. He will certainly be missed.

Lori Aubrey, writes

Mikey, I'm grateful for our time together and for the friendship that continued beyond the end of our working relationship with NOAH. Fueled by your all-encompassing commitment, together, we spent countless hours on the phone, working collaboratively in service to the albinism community for two decades. On the rare days when we were in the same city, I'm glad we took the time to take morning walks together to catch up on life and prepare for the busy day ahead. Silly moments at planning meetings and site visits (I recall daring you to climb into that tent) and sleep-deprived days leading up to and at NOAH conferences; we made the best of the situation and worked tirelessly in support of helping people experience moments of NOAH magic. Our journey together wasn't without bumps in the road, but I'll treasure the resilience of our friendship and appreciate even the rocky moments that add character to the mosaic of what was



Photo from Lori Aubrey

for many years at NOAH, "Mike and Lori." Thank you for your trust, for empowering me to grow professionally, and, most of all, for your friendship.

Donna Inman writes,

Mike's leadership and peacemaking skills were unparalleled. All our talks over the years may have started out about albinism, but they morphed into so much more.

Ethan Cohen, editor of *Albinism InSight*, writes,

Mike hired me in 2017. He was a good boss who praised quality work and raised reasonable criticisms like, "I'm getting concerned that you're not as focused on this task as it needs to be." I was happy when, for the



Photo courtesy of Rick Guidotti

first time, Mike replied, 'I read through the draft and am pleased to say that I have no edits.'

Mike once lamented the frequent amazement at people with albinism living normal lives and having problems outside of visual impairment. Yes, he said he often answered people, writing his Masters thesis was hard, but not because of albinism!

I think Mike was aware of his impact, even if he would couch his legacy with sardonic quips. He once marveled at the baby whose mother he conversed with on a pool deck in 2000 now being a seventeen-year-old Notable in our magazine.

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Above all, I saw Mike give credit to others, especially the women who form the bulk of NOAH's volunteer force. He became choked up while honoring Dr. Gail Summers in 2018 in Kansas City. "Take a look at her," he told the patients of the beloved albinism specialist, "and say thank you, Dr. Summers."

Marleena Barber writes,

Mike was the heart and driving force that advanced NOAH to the organization that it is today. I will forever hold memories of all the fun we had planning NOAH conference opening sessions, his creativity and enthusiasm, and working together to develop the NOAH Choir. He was a servant leader to our community and we are grateful.

Chris French Kramer writes,

When we were adopting our son from China in 2005, Mike was one of the first NOAH folks I talked to. He was also one of the first we met in Minneapolis at the conference in 2006. Mike was always happy to answer questions and help. He was normal and didn't ask for anything special. When I



Photo from Chris Kramer

was on the NOAH Board of Directors, he made sure we worked hard, played hard, and made connections with local families. He wanted to build relationships, increase awareness, and spread advocacy. Mike was truly professional and made NOAH an even stronger organization with his leadership. I will especially miss watching him laugh with Scott G and Tim L, the three stooges in my mind. Rest in peace, Mike!

Becca Evans writes,

I met Mike in 1993 when I was an annoying school-ager at a NI mini-conference. He was the first person with albinism, except for my sister, that I had ever met. I had a lot of fun working with him at the WI family camp and he was the coach of the Swedish Bikini team. So many laughs over the years. Rest easy, Mike, and you will be missed!



Photo from Barbara Levy Hrach.
Rowdy Shea with Mike at the
St. Louis Superstars Bowlathon

Gacia Coronado writes,
Mike was one of the first people we met in the albinism community. He shared so much wisdom with us, along with humor, candor, and kindness. He gave us confidence that we had found the right community to lean on as we raised our little guy. We feel privileged to have connected with him early on.

Brooke Fox writes,

Rest easy, Mike. You were a leader for all of us. 🍌