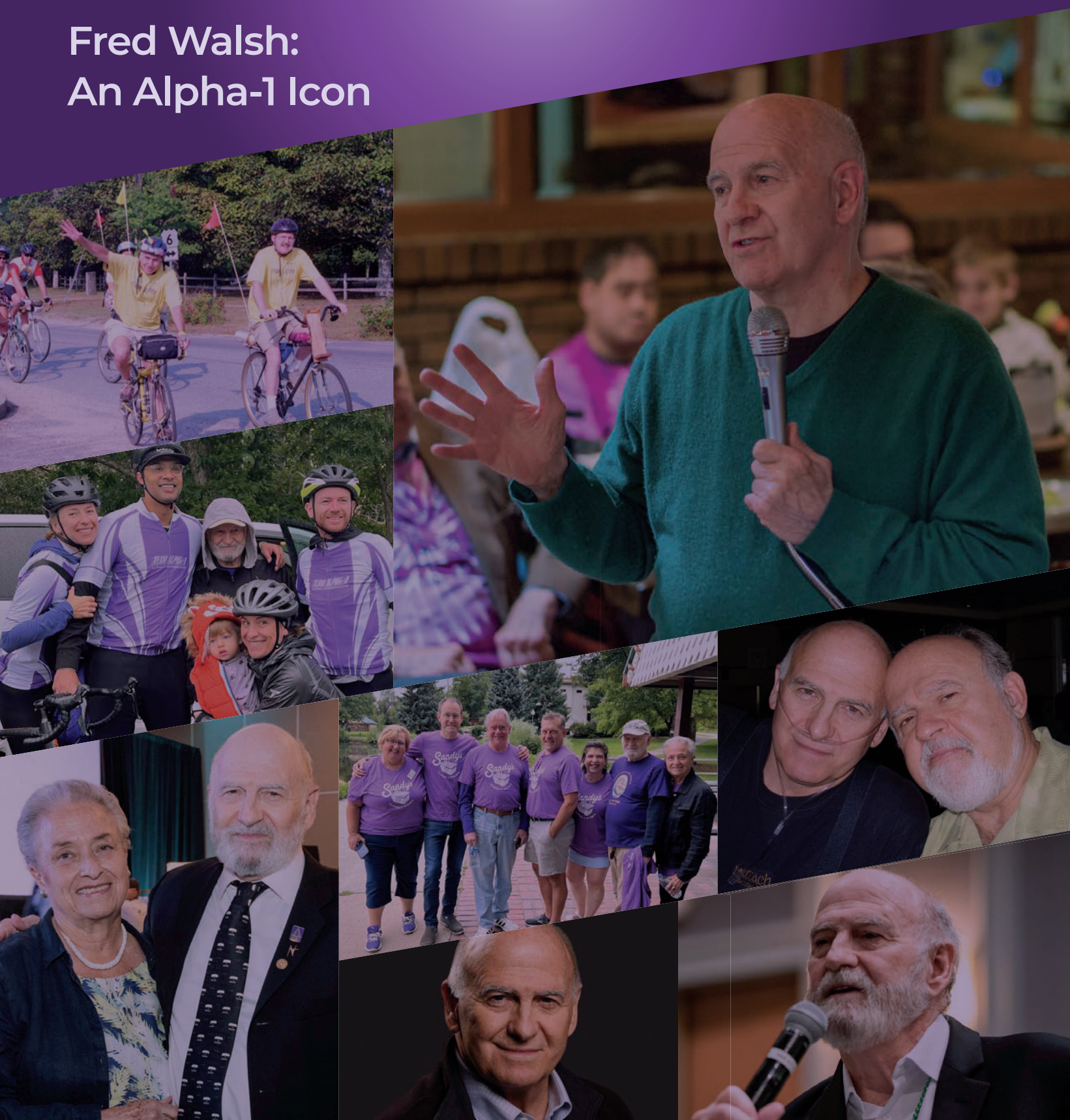
Vol. 23, No. 1 • Spring 2025

A MAGAZINE OF THE ALPHA-1 FOUNDATION

ALPHA-1-TO-ONE

Practical advice, personal experiences and pertinent news for people touched by ALPHA-1

Fred Walsh: An Alpha-1 Icon



Letter from Leadership

As we continue to celebrate the 30th Anniversary of the Alpha-1 Foundation (A1F), it is important for us to look at the history of the organization and the successes we have had. We showcased this in our incredible 30th Anniversary Commemorative Issue of the Alpha-1-to-One magazine this winter. A lot of the success that has been achieved is built on the cornerstone of the four powerful words that define our four pillars and work: Insight, Innovation, Investment, and Impact. Insight is the knowledge and the expertise that A1F provides you, creating innovation to move the field forward. A1F achieves that by investing in resources and research to propel innovation forward leading to the most important part, the impact that A1F has on patients' lives.

The dedication Alphas show to one another is truly inspiring. They generously share information and personal stories, providing mutual support throughout their journeys. In this issue, we highlight the Alpha-1 journey through diverse perspectives over the last 30 years, featuring Alphas and allies who have dedicated their lives to making a meaningful difference in the Alpha-1 community. In all we do for the patient community, we know that it is equally important to support our

ALPHA-1-TO-ONE

Practical advice, personal experiences, and pertinent news for people touched by Alpha-1, their families, and friends.

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stakeholders on the research and science side as well. We celebrate and honor scientific leadership and the impact it has made on Alphas' lives over the years. We are excited to welcome in and train the next generation of researchers and clinicians and tap their energy and new ideas to continue to impact patients' lives in real time.

In this issue of Alpha-1-to-One, we are proud to pay tribute to Fred Walsh. Fred's belief in patient empowerment resonated deeply; he championed the idea that individuals must take an active role in their health and advocate for themselves. His legacy, rooted in compassion, advocacy, and community, will undoubtedly inspire future generations of Alphas to connect, support, and strive for a brighter future.

We look forward to seeing you at the upcoming A1F National Conference from June 5-8 in Miami, Florida as we join together in celebrating the 30th anniversary! At this year's conference, you can look forward to hearing from leading Alpha-1 experts, meet with fellow Alphas, and learn about all the programs and resources available to you. Learn more about this year's conference on pages 28-29.

Please visit our website often (www.alpha1.org) to learn about upcoming events and to register online. Take a moment to visit the event map on page 38 to see where we can meet you this year.

It takes a community to help us accomplish everything that needs to be done to achieve our mission: patients, scientific leadership, researchers, and clinicians through our Clinician Research Centers (CRCs) and the Therapeutic Development Network (TDN), industry and biotech partners, government, and policymakers. It is this collective, collaborative effort that is going to help us to achieve our mission of finding a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1).

Sincerely,

Scott Santarella

President & CEO
Alpha-1 Foundation

Contributing Editors
Gennesis Corado; Cathey Henderson; Angela McBride; Shakira Molet; Miriam O'Day; Alexis Artiles Ojeda; Randel Plant; Linda Rodriguez; Scott Santarella

ALPHA-1 FOUNDATION

The Alpha-1 Foundation is committed to finding a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1) and to improving the lives of people affected by Alpha-1 worldwide.

*Diagnosed with Alpha-1 Antitrypsin Deficiency.
+Diagnosed family member.

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STAY CONNECTED

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A Tribute to Fred C. Walsh, beloved Alpha, Friend, and Advocate for the Alpha-1 Community

Fred C. Walsh passed away peacefully on September 30, 2024, at 75 years old surrounded by his family. As both the Vice Chair of the Alpha-1 Foundation Board of Directors and an AlphaNet Coordinator, Fred served as a key figure in the Alpha-1 community. Since the establishment of these organizations in 1995 by his twin brother John W. Walsh, Susan Stanley, and Sandy Lindsey, Fred dedicated his life to supporting and educating his fellow Alphas.

As a lifetime resident of Massachusetts, Fred lived in Duxbury with his wife, Pam. Together, they built a beautiful family with their two daughters, Kailey and Chase, son-in-law Michael, and two grandchildren, along with their granddog Seamus.

Fred was an active Alpha-1 patient voice on A1F's Board of Directors. In 1995, he began working for AlphaNet as a Coordinator and served in that role helping Alphas for over 29 years. In 2016, Fred received a double lung transplant, and following his recovery, he immersed himself into giving back to the Alpha-1 community. Fred was a leader and member of the hard-working Alpha-1 Support Group in Massachusetts. He helped build fundraising efforts through annual events like the Team Alpha-1 Escape to the Cape and A1F Celtic Connection.

"Fred was the quintessential Alpha, always willing to lend an ear, offer guidance and advice, and help all Alphas wherever they were in their journey. He was a champion of the A1F and AlphaNet missions, and his positive spirit, warmth, and passion are a legacy that we can all aspire to," said Scott Santarella, President and CEO, Alpha-1 Foundation.

Fred was born on February 4, 1949, in Arlington, Massachusetts. His mother, Helen, an athlete in her youth and a non-smoker, struggled with lung issues including early-onset emphysema, a diagnosis that unfortunately was not fully understood then. The loss of Fred's mother during his teenage years was a defining moment in his family's life, and Fred emerged with a strong desire to understand and address his own health issues, culminating in his diagnosis as a ZZ Alpha in 1989.

Seeking a deeper understanding of Alpha-1, Fred, along with his brother John, joined the National Institute of Health's (NIH) Alpha-1 longitudinal study in 1991, where they not only gained valuable insights about their health, but also forged connections with fellow Alphas, physicians, and researchers inspiring them to advocate for further research and community support. During his time in the study, he met many prominent Alpha-1 physicians and researchers, including Dr. Mark Brantly.

"It was my good fortune to be a friend of Freddy for more than 30 years. For much of the time I knew Freddy, he had significant shortness of breath. However, his suffering never showed because he always had a smile on his face, a joke on his lips, and a twinkle in his eye. Freddy was one of the most generous, kind, and loving people I have known on this earth. What he gave me in our 30 years of friendship, I will cherish until it is my time to say goodbye to my family and friends. I miss you, Fred," said Dr. Mark Brantly, member of the A1F Board of Directors.

After the NIH's Alpha-1 longitudinal study, the idea of A1F and AlphaNet was created, and a community was established to continue Alpha-1 research and generate funding with the mission to find a cure. Fred's extensive background in counseling and teaching led him to become one of the first AlphaNet coordinators, a position he held proudly for nearly three decades. In his role as a coordinator, he was able to connect with and guide countless Alphas in navigating their health journey, especially as they faced challenges related to access to treatment.

"Fred lived his life thinking about and serving others. He was a joy to be around. After his passing the AlphaNet Coordinator team got together and shared stories about Fred's dedication, kindness, and wonderful sense of humor. We miss him but will honor his work with ours moving forward," said Mark Delvaux, President and CEO, AlphaNet.

Fred continued to exemplify the essence of the Alpha-1 community through his work as an AlphaNet Coordinator for the Northeast region and his leadership of A1F's Board of Directors. His belief in patient empowerment resonated deeply, and he championed the idea that individuals must take an active role in their health and advocate for themselves. Fred remained hopeful for the continued growth and success of the Alpha-1 community, envisioning it as a beacon of hope for patients everywhere. His legacy, rooted in compassion, advocacy, and community, will undoubtedly inspire future generations of Alphas to connect, support, and strive for a brighter future.

This March, at the annual A1F Celtic Connection, the 2025 Shillelagh award was presented in Fred Walsh's memory to each person at the event for their courage, indefatigable determination, and indomitable fighting spirit. Each guest was presented with the gift of a traditional Shillelagh keychain to carry with pride, representing the strength and fighting spirit of Fred and the Alpha-1 community. Serving as a key figure in the Alpha-1 community, Fred was an incredible leader, both as the Vice Chair of the Alpha-1 Foundation and an AlphaNet Coordinator for 30 years. He was committed to carrying on his brother John W. Walsh's mission to finding a cure for Alpha-1.

Two special announcements were also made during the event honoring Fred's legacy. The creation of the A1F Fred C. Walsh Speaker Bureau. This new program will serve to empower Alphas to be the voice of the Alpha-1 community. The second announcement was the support from AlphaNet for a $100,000 grant designated to A1F's new testing and detection program.

As Fred would remind us to "Keep the Faith," A1F continues to work tirelessly as a testament to the community that both John and Fred built.

The Alpha-1 Journey: Then & Now

Gordon Cadwgan, PhD: Reflecting on his Alpha-1 Journey

When Gordon Cadwgan was diagnosed with Alpha-1 in January 1992, he had no idea how much the diagnosis would change, not just his life, but his life's purpose.

It started with a shortness of breath that wouldn't go away. "I was told it was exercise-induced asthma," he recalls. "My primary care doctor gave me inhalers and said, 'Come back in six months.' But it just didn't feel right." So, Gordon, a chemist at DuPont (a prominent chemical company that became a world leader in developing and manufacturing chemical products, including iconic inventions like nylon, Teflon, Kevlar, and Mylar) decided to investigate further.

He contacted the pulmonologist who had reviewed his chest X-rays and pulmonary function tests. One of the doctors in the group who had previously diagnosed an Alpha-1 patient, ordered the appropriate blood tests. "I was 48, active, had quit smoking at 30 but the bloodwork confirmed it, I had Alpha-1."

At the time, resources were limited. There was no Google, but his wife, Ruth, and he had access to the DuPont medical library. They submitted written requests for journal articles and found seven or eight scientific papers, mostly from Sweden. The outlook back then wasn't great; life expectancy was said to be around 60 years old.

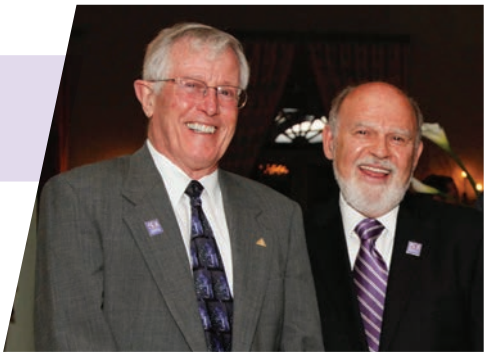
Undeterred, the Cadwgans enrolled in a five-year clinical study. Their first stop was in Philadelphia, Pennsylvania. The respiratory therapist on site was helpful, but the pulmonologist told them to 'get their affairs in order.' Not exactly the encouragement needed, and they never went back. Instead, they transferred to the National Institutes of Health (NIH) Study in Bethesda, Maryland, under Dr. Mark Brantly. "It was a whole lot better," Gordon says. "The staff cared, and the science was solid. Dr. Brantly was there; that was the turning point."

Later that same year, they attended the first national meeting of the former Alpha-1 Association in Minnesota. That's where they really started to understand the condition and meet so many others navigating this same journey.

By 1995, Gordon had retired from DuPont on disability. Ruth retired in 1999, and the couple moved to West Palm Beach, Florida, just a short drive from the A1F headquarters in Miami. In 2004, they officially became involved with A1F after being active for many years at support group meetings and education days. They were invited to join A1F committees, and Gordon was later nominated to the Board of Directors, serving in multiple positions, including secretary in 2006 and Chair of the Board from 2013-2018.

Gordon's scientific background made him a natural fit for Foundation leadership. He served on the Industry Advisory Committee and played an important role in helping launch and support The Alpha-1 Project (TAP). "TAP was a bold move," he says. "It brought together science and the Foundation's mission. Ruth and I had made the Foundation part of our estate plans, but we realized it's more impactful to give now, while the research needs it most." They believed this impactful gift would help energize the community and patients, academia, pharmaceutical and biotech companies along with public health organizations, and would continue the relentless pursuit of cures and therapies for lung and liver diseases caused by Alpha-1.

Ruth brought her creativity to fundraising. One year, she gathered neighbors and friends around the



dining table to string Alpha-1 awareness bracelets, raising $18,000 for the cause. It built Alpha-1 awareness in their community and gave everyone an easy and fun way to contribute.

Together, the Cadwgans hosted countless A1F support group meetings in their home, served on a multitude of committees, co-chaired events, and provided steady encouragement to newly diagnosed patients. “I always say we were diagnosed with Alpha-1. This has always been something we’ve faced together,” Ruth says.

“Serving on the Board and working with incredible people like John W. Walsh, Fred Walsh, the ‘Coach’, (John and Fred’s father) and the staff at A1F was an amazing and rewarding experience. Working to support research, education, and advocacy, this work became a second career with a second life. It’s been incredibly rewarding.”

Today, Gordon remains optimistic about the future of Alpha-1 research.

> CRISPR, RNA, gene therapy, it’s not science fiction anymore. We’re getting close to a real cure.
>
> **—Gordon Cadwgan, PhD**

Gordon’s advice to newly diagnosed Alphas is this: “Dive in and learn everything you can. Get involved with the Foundation, it’s a great (the best) source of support. Stay hopeful, especially younger Alphas and their families. The future is looking bright.”

Lori Mitcheroney: Today’s Alpha-1 Journey

On December 4, 2023, at the age of 60, Lori Mitcheroney received a life-changing diagnosis. She was diagnosed with Alpha-1. She was told she had moderate-severe Alpha-1-related COPD and emphysema resulting in loss of lung function, yet she never smoked a day in her life. Looking back on her health, there was nothing that would stand out and cause alarm or concern, even though she was born jaundiced, as many Alphas are. She remembers hating to run and dreading “the mile” run in middle and high school and walked it instead. Throughout her adult life, she complained to various healthcare professionals about random bouts of breathlessness. In the spring/summer of 2023, her breathing became noticeably worse, and she began having more frequent bouts of breathlessness. By October of 2023, her breathing became such a concern that it prompted further medical attention. It took two months of testing to rule out heart issues and ultimately led to her diagnosis as a ZZ Alpha.

“I feel very fortunate to live in the Boston area where I have access to top medical care. I am currently a patient of two pulmonologists who are working together to co-manage my care. One, who I will be eternally grateful to for diagnosing me, and two, my Alpha-1 specialist at my local Clinical Resource Center (CRC) that is involved in Alpha-1 research. I am fortunate to have an Alpha-1 specialist coming on board as part of my team as well.”

For a little over a year, Lori has been receiving augmentation therapy. This weekly IV infusion of alpha-1 antitrypsin protein has been collected from healthy plasma donors. It takes 900 donors to supply what is needed for just one Alpha patient’s yearly treatment. Lori is grateful to plasma donors who unselfishly give their time and plasma to those who desperately need it to survive.

“I am the first in my family to be diagnosed with Alpha-1. Early detection and diagnosis have such a bearing on the outcome of disease. Those who tend to have the best outcomes are aware of their family history, can be monitored, make healthier lifestyle choices, and receive therapy before they develop serious disease. Diagnosing Alpha-1 early means getting treatment sooner, which may help slow or prevent lung damage. Because Alpha-1 causes the same symptoms as more common conditions like COPD and asthma, it can prove especially challenging to diagnose. In fact, it can still take several years for many people with Alpha-1 to be correctly diagnosed with this condition.”

When diagnosed with a rare disease, you are thrown

into a world of the unknown and it may feel like you are all alone. However, Alpha-1 has also brought some wonderful people into Lori's life, who she otherwise would not have met. One of these people was Fred Walsh. Fred was literally the first Alpha she had ever spoken to, and their initial conversation lasted two hours, during which Fred answered so many of her questions, and shared his and his family's Alpha-1 journey. Fred was Lori's assigned AlphaNet Coordinator, and became an important mentor to her. Although Lori only knew Fred for a short time, he helped her more than he would ever know. Fred inspired Lori to become a Support Group Leader for the Massachusetts/Rhode Island Support Group, now known as the MassAlphas. In March 2024, only 3 months into her diagnosis, she took on the role along with Karin Pittsley. Karin was diagnosed just two years before Lori. Karin became a mentor and trusted friend, and Lori feels like she has known Karin her entire life. They plan to "grow old and wrinkly together, breathing with their own lungs."

Volunteering for A1F and participating in everything offered has opened the door for opportunities to meet others who are dealing with this same diagnosis. Lori feels that being with other Alphas who are kind, understanding, and supportive has helped her stay positive. Each Alpha has shared their story and journey and further strengthens the bond they have with one another.

> The Alpha-1 community has literally wrapped its arms around me. I feel a sense of belonging and acceptance and that is encouraging.
>
> **—Lori Mitcheroney**

In June 2024, about six months after diagnosis, Lori and her husband David attended the A1F National Conference. They continued their involvement this past September participating with their family in the 2024 Escape to the Cape Bike Trek. They rode 25 miles and proudly wore an Alpha-1 Angel patch on their backs, each honoring an Alpha who had lost their battle. Team Mitch raised over $6,000 in its first year!

Lori plans to do everything possible to remain healthy and focus on what she can do and not on what she can't do. She has recently started an eight-week session of pulmonary rehabilitation, continues to ride her stationary bike every day, walk outdoors whenever it is safe to do so, lift light weights—and practice yoga. She does get breathless but reminds herself that it is important that she keeps her lungs strong.

Sharing the news of this diagnosis with her children was the hardest thing she ever had to do. However, she is thankful that her diagnosis has opened the door for her kids, grandkids, and other family members who now have the knowledge and can make safer choices to protect themselves going forward. In that regard, she thinks of her diagnosis as a gift.

Lori is grateful for A1F's commitment to finding a cure. With recent advances in research, ongoing clinical trials, and emerging therapies, she is confident that we are well on our way. Her hope is that all Alphas will be here to witness just that!

Cheryl Pirozzi, MD: Caring for the Alpha of Today

Dr. Cheryl Pirozzi's journey into the field of Alpha-1 began soon after she completed her pulmonary fellowship in 2013. By 2016, she had become the Alpha-1 physician specialist leading the University of Utah's Clinical Resource Center (CRC), where she has since built strong connections with patients and researchers alike. Her focus is clear: improve the diagnosis, care, and long-term outcomes for Alpha-1 patients while navigating the challenges of a rare and often misunderstood disease.

Her interest in Alpha-1 grew out of a broader focus on the impact of the environment on lung health, initially drawing her attention to Alpha-1 as a condition particularly influenced by environmental exposure. Despite the advancements, Dr. Pirozzi highlights how delayed diagnoses continue to be a challenge.

> With any rare disease, delays in diagnosis are common, and this leads to delays in the appropriate care of patients. One ongoing struggle in Alpha-1 is educating healthcare providers to recognize when testing for Alpha-1 is appropriate, enabling earlier diagnosis and improved care for individuals with Alpha-1 and their families.
>
> **—Cheryl Pirozzi, MD**

Technology plays a pivotal role in her practice, having the advantage of electronic medical records to help facilitate obtaining testing records and imaging from other institutions. When a patient is referred after being diagnosed elsewhere, she can see the testing that led to the diagnosis, which greatly assists in the evaluation and treatment of the patient. In addition to improving patient evaluation and treatment plans, technology has transformed patient education and has improved access to patients through easier communication and the option of virtual visits. It has also facilitated education through virtual programs, both for providers and for patients.

Dr. Pirozzi first connected with A1F when she assumed her role at the University of Utah CRC. Many patients have reached out through the Foundation's website to find an Alpha-1 specialist and then were referred to her CRC. The relationships she's built with patients remain the most rewarding aspect of her work. This special patient population is actively engaged in learning about—and willing to help advance—research in the disease space. The hereditary nature of Alpha-1 means she often gets to know entire families.

Dr. Pirozzi emphasizes the importance of the collaborative network she is part of, which includes the supportive community of Alpha-1 providers and researchers.

Looking ahead, Dr. Pirozzi is enthusiastic about the future of research and its potential impact. "I get most excited about the research helping us better understand the condition, which I think in turn will lead to future improvement in care. The Alpha-1 Biomarker Consortium (A1BC) has the potential to shed valuable insight into the heterogeneity of the disease, for instance, why some people get more severe lung disease or certain types of lung disease, and others don't. I am excited to see all that we learn from that study."

The growth of clinical trials for new treatments also fuels her optimism, especially the number of potential new treatments in clinical trials that aim to improve treatment and care for Alpha-1 patients in the not-too-distant future.

To find an Alpha-1 specialist, please visit https://alpha1.org/find-an-alpha-1-specialist/

Robert Sandhaus, MD: Decades of Caring for Alphas

As we reflect on the past three decades of progress in the world of Alpha-1, it's impossible not to acknowledge the incredible journey that has shaped the lives of patients, clinicians, and researchers alike. For Dr. Robert "Sandy" Sandhaus, one of the early pioneers in this field, the path has been long, filled with both struggles and triumphs, but always with an unwavering commitment to advancing our understanding and improving care for Alpha-1 patients.

Over 50 years ago, Dr. Sandhaus first encountered Alpha-1 in 1971 while working on his PhD at Stony Brook University with Dr. Aaron Janoff, the discoverer of human neutrophil elastase, the enzyme that causes lung injury in Alpha-1. Together, they explored the mechanisms behind lung and liver disease in Alpha-1. "I stumbled into Aaron's lab after graduating from college and didn't leave until five years later," Dr. Sandhaus recalls. This early research laid the foundation for his future work with patients. In the late 1970s, after moving to the University of California, San Francisco Medical Center, Dr. Sandhaus began treating patients with Alpha-1, a move that was pivotal in his career.

In the early days, diagnosing Alpha-1 was a significant challenge. “Detection was the biggest issue,” he says. Without specific tests, many patients were misdiagnosed or missed entirely. Dr. Sandhaus and his colleagues worked to create guidelines for testing and to advocate for healthcare providers to follow them. The real breakthrough came in 1987 with the approval of augmentation therapy, which offered the first treatment specifically for Alpha-1-related lung disease.

“Before that, there were no real treatments. Augmentation therapy changed everything,” he notes. Yet, while the therapy marked a difference, the journey of treatment and care for Alpha-1 patients was far from complete. The need for education and awareness, both among healthcare providers and the general public, remained a key focus.

When Dr. Sandhaus moved to National Jewish Hospital in Denver in the 1980s, his role in the Alpha-1 community expanded. There, he established one of the largest Alpha-1 clinics in the country and became involved in the National Institutes of Health’s (NIH) Registry of Patients with Alpha-1. The clinic not only allowed him to treat a diverse group of patients but also provided critical insight into the condition’s impact on families across the country.

What Dr. Sandhaus found most rewarding, however, was the opportunity to educate his patients and their families.

> I would set aside four hours for each initial visit, encouraging patients to bring their family members for testing. It was about empowering the whole family to take charge of their health and, in turn, educate their own healthcare providers.
>
> **—Robert Sandhaus, MD**

His commitment to patient care was transformative, creating a lasting impact that resonated throughout the Alpha-1 community.

One of his proudest moments came when he facilitated the first-ever lung transplant for an Alpha-1 patient in the United States. “Convincing the lung transplant team at Washington University in St. Louis to perform the procedure was a huge victory. It showed that Alpha-1 patients could survive and thrive with the right care,” Dr. Sandhaus recollected.

Dr. Sandhaus has also played a role in the growth of A1F, joining its Board of Directors in the mid 1990s. His work with A1F helped shape the direction of Alpha-1 research, with the organization’s focus being on funding and supporting critical studies. In 2000, Dr. Sandhaus was offered the newly created position of Clinical Director of the Alpha-1 Foundation.

Reflecting on his decades of work in the field, Dr. Sandhaus emphasizes that although there have been key advancements in Alpha-1 research, there is still much work to be done. “There’s been tremendous progress in treatment,” he says. “However, I’m disappointed that Alpha-1 education hasn’t become more widespread in medical schools and residencies. That’s still one of our biggest hurdles in improving early detection and intervention.”

Looking forward, Dr. Sandhaus is optimistic about the future of Alpha-1 care. The development of new therapies for both lung and liver disease offers hope for better outcomes for patients, and the expansion of detection could change the way Alpha-1 is diagnosed and treated. “These advancements could reshape the future of Alpha-1 care,” he concludes. “We’re on the cusp of a new era, and I’m excited to see where it leads.”

Over the past 30 years, the Alpha-1 community has achieved incredible milestones, from groundbreaking therapies to increased awareness and patient advocacy. While the journey is far from over, the future of Alpha-1 is filled with promise. With continued dedication and innovation, the next chapter holds the potential to improve the lives of those affected by this rare and often misunderstood condition.

Alpha-1 Kids: The Groves Family Finds Hope

Like most parents, Samantha Modley and Adam Groves never imagined their child would be diagnosed with a rare genetic condition. At first, the symptoms were subtle, nothing that seemed out of the ordinary for a growing toddler. But soon, they became impossible to ignore. During one of their daughter Adalynn's routine pediatric visits, a bluish tint was noticed in her hands and feet, a condition called acrocyanosis. Although common in young children, it still did not sit right with Samantha and Adam. Trusting their instincts, they requested further tests be performed.

The results showed that Adalynn's liver enzyme levels were dangerously high. While the doctors initially suspected a viral infection, the levels remained elevated, prompting further testing and a referral to a pediatric gastroenterologist, Dr. Amy Guido.

"How do you prepare for something you never saw coming?" This question has echoed through Samantha's mind countless times. It's the question that defines the journey they have been on since Adalynn was diagnosed with Alpha-1 at three years of age.

"We went from thinking everything was fine, to hearing that we had to monitor our daughter closely for potential liver and lung disease," Samantha recalls. "We were overwhelmed, terrified, and angry all at once. It felt like our whole world shifted in a moment."

But instead of yielding to fear, Samantha and Adam acted. Determined to understand this diagnosis and find hope, they spent countless nights reading everything they could find on Alpha-1. “We had to understand what this meant for Adalynn and our family. And most importantly, we had to find something to hold on to,” said Samantha.

That is when they discovered A1F’s website and resources. For the first time, Samantha and Adam felt like they were not alone. A1F became their lifeline, giving their family the tools, the information, and the community they needed to navigate Adalynn’s diagnosis.

Through genetic testing, they learned that Samantha was an SZ Alpha and Adam was an MZ Alpha. Testing also confirmed that four of their five children had varying levels of Alpha-1, with Adalynn and her older brother, Brantlee, being the most affected as ZZ Alphas. The realization that this rare, genetic condition was affecting their entire family was overwhelming, but it did not stop Samantha and Adam from pushing forward.

Reflecting on this moment, Samantha and Adam wanted to understand what this diagnosis meant for each child and what they could do to protect them. Their path eventually led them to the 2024 A1F National Conference in Miami, Florida. They connected with other Alpha-1 families with children facing similar challenges and met Alpha-1 specialists that reassured them of their options and ongoing research towards therapies and a cure. For the first time since the diagnosis, Samantha and Adam found hope again.

> It was the support we didn’t know we needed. We were not just a family struggling with Alpha-1, we were part of something bigger
>
> **—Adam Groves**

Now, under the care of Alpha-1 specialists at Cincinnati Children’s Hospital, Samantha and Adam continue to monitor the liver enzyme levels of Adalynn and Brantlee. While both children’s tests have shown elevated liver markers, their doctors remain cautiously optimistic with routine follow-up appointments.

> Don’t borrow trouble. You can’t predict what will happen tomorrow, but you can choose to live today, to be there for your kids, and to learn as much as you can.
>
> **—Samantha Modley**

Today, Samantha’s advice to other parents facing similar challenges is simple:

“The journey might be tough, but you’re not alone. We’ve come so far, it’s not been easy, but I can see how much we’ve learned and how much stronger we’ve become. And that’s something we never expected to find in the middle of this journey.”

27th Gordon L. Snider (GLS) Critical Issues Workshop: Experimental Models of Alpha-1 Antitrypsin Deficiency Lung and Liver Disease

A1F joined with researchers, clinicians, and industry partners in Bethesda, Maryland for the 27th Gordon L. Snider (GLS) Critical Issues Workshop titled Experimental Models of Alpha-1 Antitrypsin Deficiency Lung and Liver Disease. The goal of GLS topical workshops is to provide new information that accelerates the journey to a cure for Alpha-1. Co-chaired by Dr. Andrew Wilson and Dr. Tamir Rashid, the overall aim of this workshop was to explore experimental models of liver and lung disease and how these models can be applied to both advance understanding of disease mechanisms and assess efficacy of potential therapeutics.

This GLS workshop surveyed the current landscape of experimental AATD modeling, touching on models long used for this purpose and emergent models not yet applied toward this goal. As each individual model by definition has relative strengths and weaknesses, one focus will be to understand how best to apply each and how complementary approaches might be collectively applied to address existing knowledge gaps.

The GLS Critical Issues Workshop Series facilitates expert exchanges and answers important questions to stimulate further research. These conferences are a cornerstone of A1F's efforts, igniting enthusiasm within the field and solidifying its reputation as a leader in the rare disease community.

> This is an incredible time in Alpha-1 research. We have made amazing technical advances that we are starting to see applied to Alpha-1 Antitrypsin Deficiency, and we are incredibly excited about the potential application of those advances in our patients
>
> **—Andrew Wilson, MD**
> **Alpha-1 Foundation**
> **Scientific Director**

We extend our sincere thanks to the GLS moderators, presenters and sponsors

The workshop was divided into two sections, “The Liver”, moderated by Jeffrey Teckman, MD, and “The Lung”, moderated by Andrew Wilson, MD.

GLS moderators:

Jeffrey Teckman, MD
moderated the GLS workshop on Alpha-1 liver

Andrew Wilson, MD
moderated the GLS workshop on Alpha-1 lung

GLS presenters:

Leo van Grunsven, PhD
Vrije Universiteit Brussel

Kentaro Iwasawa, MD
Cincinnati Children’s Hospital

Melanie Koenigshoff, MD, PhD
University of Pittsburgh School of Medicine

Carly Merritt, BA
Boston University School of Medicine

Chris Mueller, PhD
Sanofi

Francesca Polverino, MD, PhD
Baylor College of Medicine

S. Vamsee Raju, PhD
University of Alabama at Birmingham

Foad Rouhani, MD, PHD
Francis Crick Institute

David Rudnick, MD, PhD
Washington University School of Medicine

Amy Stoddard, PhD
MIT, Boston University

Adam Syanda
Imperial College London

GLS Sponsors

Ongoing commitment from AlphaNet, Beam Therapeutics, CSL, Grifols, and Takeda provided support to conduct this workshop.

Zemaira®
alpha$_1$-proteinase inhibitor (Human)

Discover the ZEMAIRA Difference

AND BE CONFIDENT WITH YOUR ALPHA-1 THERAPY

Get ready to discover all that ZEMAIRA has to offer:

Convenience

Low-volume infusion in as little as 15 minutes*, with no refrigeration required and available in 3 sizes: 1-, 4-, and 5-gram vials

Purity & Efficacy

Highly purified augmentation therapy approved by the FDA with purity achieved through a rigorous manufacturing process, proven in clinical trials to raise and maintain levels of the Alpha-1 protein

ZEMAIRA Connect℠

Ongoing support to help you start or stay on treatment

Learn more at ZEMAIRA.com

*Average infusion time is based on an infusion rate of 0.08 mL/kg/min for a 165-lb patient. Individual experiences may vary.

Important Safety Information

ZEMAIRA®, Alpha$_1$-Proteinase Inhibitor (Human), is indicated to raise the plasma level of alpha$_1$-proteinase inhibitor (A_1-PI) in patients with A_1-PI deficiency and related emphysema. The effect of this raised level on the frequency of pulmonary exacerbations and the progression of emphysema have not been established in clinical trials.

ZEMAIRA may not be suitable for everyone; for example, people with known hypersensitivity to components used to make ZEMAIRA, those with a history of anaphylaxis or severe systemic response to A1-PI products, and those with certain IgA deficiencies. If you think any of these may apply to you, ask your doctor.

Early signs of hypersensitivity reactions to ZEMAIRA include hives, rash, tightness of the chest, unusual breathing difficulty, wheezing, and feeling faint. Immediately discontinue use and consult with physician if such symptoms occur.

In clinical studies, the following adverse reactions were reported in at least 5% of subjects receiving ZEMAIRA: headache, sinusitis, upper respiratory infection, bronchitis, fatigue, increased cough, fever, injection-site bleeding, nasal symptoms, sore throat, and swelled blood vessels.

Because ZEMAIRA is made from human blood, the risk of transmitting infectious agents, including viruses and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent and its variant (vCJD), cannot be completely eliminated.

Please see full prescribing information for ZEMAIRA.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

You can also report side effects to CSL Behring's Pharmacovigilance Department at 1-866-915-6958.

CSL

1020 First Avenue, PO Box 61501
King of Prussia, PA 19406-0901 USA
www.CSLBehring.com www.ZEMAIRA.com

USA-ZMR-0241-FEB25

ZEMAIRA®, Alpha$_1$-Proteinase Inhibitor (Human)
lyophilized powder for reconstitution for intravenous use
Initial U.S. Approval: 2003

BRIEF SUMMARY OF PRESCRIBING INFORMATION
These highlights do not include all the information needed to use ZEMAIRA safely and effectively. See full prescribing information for ZEMAIRA.

----------INDICATIONS AND USAGE----------

- ZEMAIRA is an alpha$_1$-proteinase inhibitor (A_1-PI) indicated for chronic augmentation and maintenance therapy in adults with A_1-PI deficiency and clinical evidence of emphysema.
- The effect of augmentation therapy with ZEMAIRA or any A_1-PI product on pulmonary exacerbations and on the progression of emphysema in A_1-PI deficiency has not been demonstrated in randomized, controlled clinical studies.
- ZEMAIRA is not indicated as therapy for lung disease patients in whom severe A_1-PI deficiency has not been established.

----------DOSAGE AND ADMINISTRATION----------
For intravenous use after reconstitution only.

- The recommended weekly dose of ZEMAIRA is 60 mg/kg body weight. Dose ranging studies using efficacy endpoints have not been performed with ZEMAIRA or any A_1-PI product.
- Administer through a suitable 5 micron infusion filter (not supplied) at room temperature within 3 hours after reconstitution.
- Do not mix with other medicinal products. Administer through a separate dedicated infusion line.
- Administer at a rate of approximately 0.08 mL/kg/min as determined by the response and comfort of the patient.
- Monitor closely the infusion rate and the patient's clinical state, including vital signs, throughout the infusion. Slow or stop the infusion if adverse reactions occur. If symptoms subside promptly, the infusion may be resumed at a lower rate that is comfortable for the patient.

----------DOSAGE FORMS AND STRENGTHS----------

ZEMAIRA is supplied in a single-dose vial containing approximately 1000 mg, 4000 mg, or 5000 mg of functionally active A_1-PI as a white to off-white lyophilized powder for reconstitution with 20 mL, 76 mL, or 95 mL of Sterile Water for Injection, USP. The amount of functional A_1-PI is printed on the vial label and carton.

----------CONTRAINDICATIONS ----------

- History of anaphylaxis or severe systemic reactions to ZEMAIRA or A_1-PI protein.
- Immunoglobulin A (IgA)-deficient patients with antibodies against IgA, due to the risk of severe hypersensitivity.

----------WARNINGS AND PRECAUTIONS----------

- Observe any signs of hypersensitivity such as tachycardia, hypotension, confusion, syncope, oxygen consumption decrease, and pharyngeal edema when administering ZEMAIRA to patients with known hypersensitivity to an A_1-PI product.
- Patients with selective or severe IgA deficiency can develop antibodies to IgA and, therefore, have a greater risk of developing potentially severe hypersensitivity and anaphylactic reactions. If anaphylactic or severe anaphylactoid reactions occur, discontinue the infusion immediately.
- Because ZEMAIRA is made from human blood, it may carry a risk of transmitting infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.

----------ADVERSE REACTIONS----------

- Serious adverse reactions reported following administration of ZEMAIRA in pre-licensure clinical trials included one event each in separate subjects of bronchitis and dyspnea, and one event each in a single subject of chest pain, cerebral ischemia and convulsion.
- The most common adverse reactions occurring in at least 5% of subjects receiving ZEMAIRA in all pre-licensure clinical trials were headache, sinusitis, upper respiratory infection, bronchitis, asthenia, cough increased, fever, injection site hemorrhage, rhinitis, sore throat, and vasodilation.

To report SUSPECTED ADVERSE REACTIONS, contact CSL Behring Pharmacovigilance at 1-866-915-6958 or FDA at 1-800-FDA-1088 or *www.fda.gov/medwatch.*

Based on January 2024 revision

Cleveland Clinic

ALPHA-1 FOUNDATION

Alpha-1 Foundation Continuing Medical Education Series

The Alpha-1 Foundation (A1F) and the Cleveland Clinic are partners on a healthcare professional medical education series! Here are some highlights of the program. To take the course, visit: **alpha1.org/continuing-medical-education-credits/**

- This educational series is designed to aid in the knowledge, diagnostic, and treatment competence needs of healthcare providers to diagnose, treat, and provide better care for Alpha-1 patients.
- The professional education program targets various types of healthcare professionals, including pulmonologists, hepatologists, pediatric lung and liver physicians, liver and lung transplant physicians, nurse practitioners, physician assistants, genetics counselors, respiratory therapists, and internal medicine/general medicine physicians.
- Each video, as part of this series, includes a patient testimonial about their Alpha-1 experience.
- This online program has been approved for *AMA PRA Category 1 Credits™*
- A1F has partnered with Jamie Stoller, MD, and the Cleveland Clinic, which is accrediting the program to develop this new healthcare professional, medical education program.

Thank you to patients, Dr. Stoller and his Cleveland Clinic team, members of A1F's Medical and Scientific Advisory Committee, several board of directors members, and Cleveland Clinic clinical staff who volunteered to record videos to help us create a robust Alpha-1 Foundation Continuing Medical Education Series.

Ice Cream For Alpha-1

#IceCreamForAlpha1

ALPHA-1 FOUNDATION

Looking to make a difference in a fun, family-friendly way to support the Alpha-1 Foundation (A1F)? We've got a sweet idea for you!

Host an **Ice Cream for Alpha-1** fundraiser! Bring your family, friends, and neighbors together to enjoy delicious treats while raising awareness and funds for Alpha-1 research toward a cure.

Make a Difference

By hosting an Ice Cream for Alpha-1 fundraiser, you will raise funds and awareness for Alpha-1 research and related programs. It's a sweet way to give back to the Alpha-1 community while enjoying a delicious treat!

It's Easy & Fun

No need for fancy planning. We've made it super simple! Gather some ice cream, toppings, and a group of friends. A1F will provide the tools for making your event a success, such as:

- Fundraising materials – flyers, social media templates
- Ice cream donation tips to ask local partners to help lower your costs
- Help with creating your online fundraising page

Flexibility & Creativity

You can host your Ice Cream for Alpha-1 fundraiser at home, work, school, or even a local park. Keep it small or go big with games, raffles, and entertainment.

Get Incentives

When you host an Ice Cream for Alpha-1 fundraiser, you can win amazing rewards including:

- Giveaways based on different fundraising levels
- Exclusive Ice Cream for Alpha-1 Starter Kit
- Recognition as a top fundraiser in the Alpha-1 community

Ready to scoop up some fun and make a difference? Sign up today to host your Ice Cream for Alpha-1 fundraiser and earn those sweet rewards!

Contact Irene Calderon, A1F Development Manager at **icalderon@alpha1.org**

For more information, visit:
give.alpha1.org/A1Ficecreamforalpha12025

Plan your local Ice Cream fundraiser today!

READY-TO-INFUSE

PROLASTIN® C LIQUID

alpha$_1$-proteinase inhibitor (human)

The #1 prescribed alpha-1 therapy for more than 30 years[1]

- **15-minute** infusion time
- **Proven** to effectively raise the alpha$_1$ antitrypsin protein levels in patients with severe alpha$_1$-antitrypsin deficiency, also known as alpha-1
- The **PROLASTIN DIRECT®** program gives you the confidence that ongoing personalized support is there for you when needed

Reference: 1. Data on file, Executive Summary, Grifols.

Steve M. and his wife, Ellen.
Steve has been on therapy since 2007.

Visit our website, **www.prolastin.com/LIQUID,** for more information and patient-friendly resources.

Important Safety Information

PROLASTIN®-C LIQUID is an alpha$_1$-proteinase inhibitor (human) (alpha$_1$-PI) indicated for chronic augmentation and maintenance therapy in adults with clinical evidence of emphysema due to severe hereditary deficiency of alpha$_1$-PI (alpha$_1$-antitrypsin deficiency).

Limitations of Use

- The effect of augmentation therapy with any alpha$_1$-PI, including PROLASTIN-C LIQUID, on pulmonary exacerbations and on the progression of emphysema in alpha$_1$-PI deficiency has not been conclusively demonstrated in randomized, controlled clinical trials
- Clinical data demonstrating the long-term effects of chronic augmentation or maintenance therapy with PROLASTIN-C LIQUID are not available
- PROLASTIN-C LIQUID is not indicated as therapy for lung disease in patients in whom severe alpha$_1$-PI deficiency has not been established

PROLASTIN-C LIQUID is contraindicated in immunoglobulin A (IgA)-deficient patients with antibodies against IgA or patients with a history of anaphylaxis or other severe systemic reaction to alpha$_1$-PI products.

Hypersensitivity reactions, including anaphylaxis, may occur. Monitor vital signs and observe the patient carefully throughout the infusion. If hypersensitivity symptoms occur, promptly stop PROLASTIN-C LIQUID infusion and begin appropriate therapy.

Because PROLASTIN-C LIQUID is made from human plasma, it may carry a risk of transmitting infectious agents, eg, viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent, and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent. This also applies to unknown or emerging viruses and other pathogens.

The most common adverse reactions during PROLASTIN-C LIQUID clinical trials in >5% of subjects were diarrhea and fatigue, each of which occurred in 2 subjects (6%).

Please see brief summary of the full Prescribing Information for PROLASTIN-C LIQUID on adjacent page.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

GRIFOLS

PROLASTIN®-C LIQUID

Alpha$_1$-Proteinase Inhibitor (Human)

HIGHLIGHTS OF PRESCRIBING INFORMATION

These highlights do not include all the information needed to use PROLASTIN-C LIQUID safely and effectively. See full prescribing information for PROLASTIN-C LIQUID.

PROLASTIN-C LIQUID
(Alpha$_1$-Proteinase Inhibitor [Human])
Solution for Intravenous Injection

Initial U.S. Approval: 1987

----------INDICATIONS AND USAGE----------

PROLASTIN®-C LIQUID is an Alpha$_1$-Proteinase Inhibitor (Human) (Alpha$_1$-PI) indicated for chronic augmentation and maintenance therapy in adults with clinical evidence of emphysema due to severe hereditary deficiency of Alpha$_1$-PI (alpha$_1$-antitrypsin deficiency).

Limitations of Use:

- The effect of augmentation therapy with any Alpha$_1$-PI, including PROLASTIN-C LIQUID, on pulmonary exacerbations and on the progression of emphysema in Alpha$_1$-PI deficiency has not been conclusively demonstrated in randomized, controlled clinical trials.
- Clinical data demonstrating the long-term effects of chronic augmentation or maintenance therapy with PROLASTIN-C LIQUID are not available.
- PROLASTIN-C LIQUID is not indicated as therapy for lung disease in patients in whom severe Alpha$_1$-PI deficiency has not been established.

----------DOSAGE AND ADMINISTRATION----------

For intravenous use only.

- Dose: 60 mg/kg body weight intravenously once per week.
- Dose ranging studies using efficacy endpoints have not been performed with any Alpha$_1$-PI product, including PROLASTIN-C LIQUID.
- Administration: 0.08 mL/kg/min as determined by patient response and comfort.

----------DOSAGE FORMS AND STRENGTHS----------

For injection: approximately 500 mg (10 mL), 1,000 mg (20 mL) and 4,000 mg (80 mL) of a solution for injection in single-dose vials.

----------CONTRAINDICATIONS----------

- Immunoglobulin A (IgA) deficient patients with antibodies against IgA.
- History of anaphylaxis or other severe systemic reaction to Alpha$_1$-PI.

----------WARNINGS AND PRECAUTIONS----------

- Severe hypersensitivity and anaphylactic reactions may occur in IgA deficient patients with antibodies against IgA. Discontinue administration of the product and initiate appropriate emergency treatment if hypersensitivity reactions occur.
- Because PROLASTIN-C LIQUID is made from human plasma, it may carry a risk of transmitting infectious agents, e.g., viruses, the variant Creutzfeldt-Jakob disease (vCJD) agent, and, theoretically, the Creutzfeldt-Jakob disease (CJD) agent.

----------ADVERSE REACTIONS----------

The most common adverse reactions during PROLASTIN-C LIQUID clinical trials in > 5% of subjects were diarrhea and fatigue, each of which occurred in 2 subjects (6%).

To report SUSPECTED ADVERSE REACTIONS, contact Grifols Therapeutics LLC at 1-800-520-2807 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

GRIFOLS

Grifols Therapeutics LLC
Research Triangle Park, NC 27709 USA
U.S. License No. 1871 **Revised: 5/2020**

3062338/3062339

A1F VIRTUAL WALK 2025

#A1FVW25

This November, join the **A1F Virtual Walk 2025** and show your support for people impacted by Alpha-1 Antitrypsin Deficiency (Alpha-1). Whether you're walking for yourself, a loved one, a friend, or in memory of someone special, every step helps raise awareness and fund vital Alpha-1 research and related programs during **Alpha-1 Awareness Month**.

Pick any date, time, and place in November to participate in your neighborhood, at a local park, on your favorite trail, or even indoors. Get creative and set your personal goal! Whether it's a solo stroll or a team walk, it's all about getting out, moving, and making a difference.

Celebrating 30 Years of Impact

This year's walk is extra special as we celebrate the Alpha-1 Foundation's 30th Anniversary. That's three decades of advancing research, raising awareness, and building a strong, supportive community. Let's celebrate this milestone together—one step at a time.

As part of this year's walk, we're introducing a personalized button you can wear and share, highlighting who you walk for. Whether it's someone you love, someone you've lost, or the entire Alpha-1 community—let your walk tell your story.

Share Your Story

Post your A1F Virtual Walk photos and stories using #A1FVW25 and help inspire others to get involved. Your voice brings awareness, connection, and hope to the Alpha-1 community.

How to Participate:

- Register online: give.alpha1.org/A1FVirtualWalk25
- $30 registration includes the official A1F Virtual Walk 2025 T-shirt
- Track your activity & fundraising efforts using the "Good Move" app
- Walk individually, join a team, or form a team—every step counts!

Let's move together—wherever you are—to honor, remember, and raise awareness for those impacted by Alpha-1. #A1FVW25 #Alpha1Awareness

ALPHA-1 FOUNDATION

INNOVATION INSIGHT INVESTMENT IMPACT 30th 1995 2025

For more info, contact Irene Calderon at icalderon@alpha1.org

Make Your Legacy Go Further

Your legacy can support the Alpha-1 Foundation (A1F), not just today, but for years to come.

Many A1F supporters have included a gift in their estate plans to make a lasting impact at no cost today.

To learn more about planned giving and leaving a legacy, visit:
alpha1.org/planned-giving/

For more information about joining the Alpha-1 Legacy Society, visit:
alpha1.org/alpha-1-legacy-society/

For additional information or to discuss planned gifts to A1F, please contact Angela McBride at amcbride@alpha1.org or call 1-877-228-7321, ext. 233.

ALPHA-1 FOUNDATION

INNOVATION 30th INVESTMENT INSIGHT IMPACT 1995 2025

John W. Walsh Alpha-1 Home Infusion Act Reintroduced in 119th Congress: HR #2343

On March 26, 2025, Representatives María Elvira Salazar (R-FL) and Chellie Pingree (D-ME) reintroduced the John W. Walsh Alpha-1 Home Infusion Act. If passed, certain Medicare beneficiaries living with Alpha-1 would be able to receive essential augmentation infusions at home. Representatives Chris Smith (R-NJ), Hank Johnson (D-GA), Burgess Owens (R-UT), Eleanor Holmes Norton (D-DC), Young Kim (R-CA), David Rouzer (R-NC), and Paul Tonko (D-NY) are original co-sponsors of the bill.

A1F and the entire patient community are thrilled with the announcement of the reintroduction of the John W. Walsh Alpha-1 Home Infusion Act. A1F expressed gratitude to Congresswoman Salazar for her continued support in sponsoring this important initiative and her commitment to Alphas nationwide. The perseverance of the community in securing co-sponsors to advance the bill forward is commendable, and A1F looks forward to collaborating toward success this term.

"Access to home-based care reduces healthcare costs while giving people dignity and peace of mind as they receive quality care in their home," said Rep. Salazar. "I am proud to lead this legislation, which would make life easier for Medicare patients struggling with this rare genetic condition. Many immunocompromised Alpha-1 patients were unable to access critical, safe, and effective therapies during the pandemic due to outdated Medicare restrictions on home infusion. The bipartisan John W. Walsh Alpha-1 Home Infusion Act will ensure that patients living with Alpha-1 can receive the lifesaving care they need—comfortably and affordably at home. This commonsense, game-changing legislation will not only improve health outcomes and quality of life, it will also help reduce overall healthcare costs. It's exactly the kind of meaningful, patient-centered policy the American people deserve from their elected leaders."

This reintroduction of the bill presents a tremendous opportunity to continue generating awareness of Alpha-1. In the past, A1F has collaborated with other like-minded organizations to advance issues that improve the lives of individuals living with Alpha-1. These efforts have led to the enactment of numerous advancements and notable progress for Alphas and others with rare genetic diseases.

Obtaining the right to have home infusions provided by Medicare Part B has long been a priority for the Alpha-1 community. During the COVID-19 Public Health Emergency, the administration introduced billing flexibility intended to allow home infusions under Medicare Part B or a relaxed interpretation of disability for those on Medicare Part D to receive home infusions. Since 2020, A1F's goal has been to achieve a permanent change in Medicare law ensuring Alpha-1 patients, whose age or disability qualifies them for Medicare, can access home infusions.

"Thank you to Congresswoman Salazar for making this legislation a reality in the 119th congressional session. We are grateful for the reintroduction of The John W. Walsh Alpha-1 Home Infusion Act for patient access to home infusions for our community. A1F has worked tirelessly so that neither age nor disability will interfere with the continuation of care when transitioning to the Medicare system. This will cement the next step forward in improving the lives of Alphas for generations to come, alleviating the burdens that come with a diagnosis of Alpha-1 and the resulting costs," said Scott Santarella, President and CEO, Alpha-1 Foundation.

A1F encourages supporters to get their representatives signed onto the bill. Those interested in getting involved should contact Jeanne Kushner, Senior Director of Communications & Public Policy, at jkushner@alpha1.org

Your Quick Guide to Alpha-1 Foundation Patient Programs, Services, and Resources

Each A1F program is designed with you, the Alpha-1 community, in mind to address the unique needs you face every day. Here is a quick guide to finding the answers to your Alpha-1 questions.

Alpha-1 Foundation (A1F)

alpha1.org | (877) 228-7321
A1F provides resources, education, and information on testing and diagnosis for healthcare providers and people affected by Alpha-1. It funds cutting-edge research to find treatments and a cure and supports worldwide detection of Alpha-1. From funding breakthrough research to hosting programs and events that keep our community strong and healthy until we find a cure, no other organization does more for families with Alpha-1.

A1F Patient Information Line

alpha1.org/patient-information-line | (800) 245-6809
Provides support to newly diagnosed Alphas and their families seeking basic information and help on a range of Alpha-1-related topics such as Alpha-1 testing, connecting with a peer guide, finding an Alpha-1 specialist, and requests for resources.

A1F Genetic Counseling Services

alpha1.org/genetic-counseling | (855) 476-1227
A1F partners with the University of Florida to provide free genetic counseling services to Alphas, their family members, healthcare providers, and other individuals considering testing or in need of support. Genetic counseling services help patients understand their genetic risk for developing lung and liver disease, as well as communicate that information to family members.

A1F Support Group Network

alpha1.org/find-a-support-group | (877) 346-3212
A collective of Alpha-1 support groups around the country committed to providing support and improving the quality of life of people affected by Alpha-1. Visit the A1F website to browse our database to locate an A1F support group near you. Many support groups also meet virtually, and you are able to join from anywhere.

Building Friends for a Cure

alpha1.org/building-friends-for-a-cure | (877) 228-7321 ext. 319
Building Friends for a Cure (BFC) is a peer-to-peer fundraising program that brings the Alpha-1 community together to promote awareness, increase engagement, and raise necessary funds for Alpha-1 research and programs.

A1F Clinical Resource Centers (CRCs)

alpha1.org/find-an-alpha-1-specialist
An integrated network of research institutions and physicians specializing in Alpha-1 treatment, education, and care, CRCs provide comprehensive care to Alphas, including specialized care for lung disease and liver disease. Visit our website to browse our database to find a doctor specializing in Alpha-1. Filter by location or area of expertise to narrow down your search.

The Alpha-1 Research Registry

alpha1.org/join-the-alpha-1-research-registry | (877) 228-7321 ext. 252

A confidential database of Alphas with one or two abnormal Alpha-1 genes that gives patients the opportunity to provide information to help advance research on the condition through questionnaires and clinical trials. It provides access to experts on Alpha-1 care. People enrolled have an ongoing opportunity to participate directly in clinical trials of new therapeutic approaches, in addition to other research opportunities.

Alpha-1 Kids

alpha1.org/alpha-1-kids | (877) 346-3212

Information, support, and resources for families of Alpha infants, children, teens, and young adults transitioning to independent care. The Parents of Alpha-1 Kids (PAK) Virtual Support Group brings together families with Alpha-1 to share experiences and offer support. A1F provides travel scholarships for families to attend the A1F National Conference. The annual conference features a dedicated track with sessions relating to the care of Alpha-1 children, young adults, and their families, and an Alpha-1 Kids room with activities so parents can attend the sessions. The conference provides families with opportunities to network with other affected families, access leading physicians, and learn about the latest research and resources from renowned pediatric liver doctors.

Join the Alpha-1 Research Registry

ALPHA-1 FOUNDATION Research Registry

We are recruiting for Alpha-1-related studies and need your participation!

We encourage you and your family members to join the Alpha-1 Research Registry to help advance Alpha-1 research, diagnosis, and treatment.

Anyone diagnosed with Alpha-1 can join the Registry in three steps:

1. Complete a Registration Form
2. Sign the Informed Consent
3. Complete the Questionnaire

To enroll or for more information:

alpha1.org/join-the-alpha-1-research-registry

2025 ALPHA-1 FOUNDATION NATIONAL CONFERENCE

MIAMI, FL | JUNE 6-8, 2025

Join A1F in celebrating its 30th Anniversary!

Visit ***alpha1.org/national-conference/*** to learn more and register today.

#A1FNC25

CONFERENCE AT A GLANCE

What to look forward to at this year's conference!

THURSDAY, JUNE 5TH

- Alpha Angels Memorial Service

FRIDAY, JUNE 6TH

- Official conference kickoff
- Empowering general session geared toward Alpha-1 patients including the **Alpha Empowerment Hour**
- Exhibit Hall Grand Opening
- An **afternoon track** with educational and empowering sessions
- Alpha-1 Parents Meet & Greet
- Dinner reception and awards

SATURDAY, JUNE 7TH

- Enlightening general session geared toward Alpha-1 research including an **Alpha-1 Research Panel** & **Emerging Therapies in Alpha-1 presentations**
- **Three (3) afternoon tracks** with educational presentations on a range of Alpha-1 topics
- Dinner reception and entertainment

SUNDAY, JUNE 8TH

- A farewell *Ice Cream for Alpha-1* Brunch you won't want to miss!

CONFERENCE INFORMATION

CONFERENCE REGISTRATION

Register: alpha1.org/national-conference/
For questions, call (877) 228-7321, ext. 323

DATES TO KEEP IN MIND

April 15th: Early Bird Registration Deadline*
May 5th: Hotel Reservation Deadline
May 15th: In-Person Registration Deadline
*Register by this date to guarantee a conference bag / virtual package

CONFERENCE HOTEL

Hilton Miami Downtown
1601 Biscayne Boulevard
Miami, Fl 33132 (305) 374-0000

PATIENT & FAMILY MEMBER HOTEL ROOM RESERVATIONS

Online: alpha1.org/national-conference/
By phone: (800) 445-8667
Patient Rate: $169 / night plus taxes & fees
Group Code: 2025 Alpha-1 National Conference
Rate Deadline: May 5th

OXYGEN TRAVEL FUND

Oxygen & equipment for Alphas in financial need to travel to Alpha-1 educational events is available. To apply, please call (877) 228-7321 ext. 251 with at least 30 days notice.

AGENDA & FAQS

For the detailed Agenda & Things To Know, visit: alpha1.org/national-conference. A virtual option is available for those who are unable to attend in person.

PLATINUM SPONSORS

AlphaNet | CSL | Grifols | Takeda

GOLD SPONSOR

Accredo by Evernorth

ALPHA-1 FOUNDATION

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Ask the Alpha Doc

At the January 2025 Virtual Education Day, the audience of over 450 attendees asked live questions of our Alpha-1 expert presenters on the virtual platform. We have highlighted the top questions that were referenced in the Alpha-1 Lung and Alpha-1 Liver Updates.

Your Alpha-1 Liver Questions Answered by Jeffrey Teckman, MD

Professor of Pediatrics & Biochemistry, Saint Louis University, Pediatric Gastroenterology and Hepatology, Cardinal Glennon Children's Hospital, A1F Clinical Resource Center (CRC) Physician

Q Do medications administered for other conditions, such as statins for cholesterol, have an impact on liver disease in Alphas?

A: Yes, many kinds of medications are processed in the liver and have a risk of liver toxicity. Sometimes, a liver already sick from something else, like Alpha-1, is more susceptible to toxicity. However, in the case of Alpha-1, this seems to be uncommon. Usually, the use of statins works out fine, but it is best to discuss it with your doctor first. Tylenol in package [normal] doses is typically fine. There is some caution about high use of non-steroidal anti-inflammatory drugs "NSAIDS" (ex: Ibuprofen).

Q How often should a lung-affected Alpha do blood tests to check liver function? If there are no liver symptoms, do you need to do further testing such as imaging, like a FibroScan or liver biopsy? Does bloodwork during an annual physical exam give any indication of liver disease? What blood tests should I be asking for?

A: All ZZ and SZ individuals need annual lung and liver check-ups by a physician who is knowledgeable about the lung and liver risks of Alpha-1. Just like a lung check-up is more than just one test, the liver check-up is a combination of the person's history (how they feel, do they have liver-related symptoms), their physical exam related to the liver—and then various liver tests. What tests need to be administered have to do with what the history and physical exam show and the patient's other details. Most people get a baseline liver ultrasound at diagnosis, but that gets repeated. Many people don't get an ultrasound annually but instead get a measure of "liver stiffness." Liver stiffness helps understand if dangerous scar tissue is building up in the liver. That can be done from Vibration Controlled Transient Elastography ("FibroScan"). Some other kinds of elastography are estimated with a panel of blood tests such as the AST-platelet ratio or "FIB4" test. Further recommendations in the area of liver disease follow-up are currently being developed. The liver does many kinds of jobs, and therefore many kinds of tests are needed to understand the status of each of the liver's activities. There are panels of liver tests which help the doctor do this, but they must be interpreted in the context of the history, physical exam, and everything else going on with the patient. Liver blood tests, alone, are not a thorough liver check-up.

Q What are symptoms of Alpha-1 liver disease in a lung-affected Alpha?

A: Symptoms of liver disease can be very mild, and often mistaken for something else, until the liver is very sick. Many people may feel tired, have trouble sleeping, feel itchy, have weight gain or loss, abdominal pain, changes in urination, or changes in breathing related to liver disease. Severe liver symptoms can include jaundice (yellow rash), confusion, serious bleeding of various kinds, swelling in the body and even coma. This is why annual liver checkups are needed, as symptoms alone make it hard to identify liver disease until it is very advanced.

Helpful Tips for Alphas:

1. When traveling, always remember to bring all your prescriptions, especially for portable oxygen.
2. When coming out of the shower, use a robe to dry off and take a minute to catch your breath.
3. When incorporating exercise into your daily routine, walk indoors during hot summer months or cold winter months.

Your Alpha-1 Lung Questions Answered by Brooks Thomas Kuhn, MD, MAS

Assistant Professor of Medicine, UC Davis Health, A1F Clinical Resource Center (CRC) Physician

Q I am a 73- year-old recently diagnosed Alpha with both COPD and emphysema, is it worth starting weekly augmentation therapy at my age?

A: This is an excellent question and one deserving of a detailed conversation with a clinician at a designated A1F Clinical Resource Center (CRC). The short answer is that not all patients with Alpha-1 require augmentation therapy. Factors that influence the decision to start weekly augmentation therapy—which is a significant personal commitment—include severity of the COPD/emphysema (with augmentation most strongly recommended if FEV_1 <65% predicted), individual rate of lung decline, comorbidities/global health, the type of Alpha-1 mutation and blood level, and access/ability to start therapy. Age is also a factor, as augmentation does not reverse or cure COPD/emphysema, but rather slows the rate of lung loss from an accelerated rate that can occur with Alpha-1 to the rate people without Alpha-1 lose lung function due to aging.

Q Do Alpha-1 levels fluctuate with infection? If so, when is the ideal time to obtain your levels to reflect the average?

A: Yes, Alpha-1 levels can increase many-fold with infection, as Alpha-1 is an acute phase reactant, increasing in amount to balance inflammation and mitigate damage to tissues. While levels may be deceptively high during infections, very severe deficiency (i.e., ZZ) will persistently remain below the normal expected blood level. In clinical practice, I prefer to screen using phenotype/genotype, as this approach will better detect specific mutations and can be reliably tested at almost any time or context. The best time to check is at least a few weeks after any significant infection. Some clinicians check blood markers of systemic inflammation to contextualize at this time as well (e.g., C-reactive protein).

Q Are there prophylactic treatment options for ZZ Alphas with normal liver and lung functions and no current disease manifestation?

A: Yes, but I suspect my answer is not what you expected. Too often in medicine, we gloss over healthy living advice: avoiding smoking, maintaining a normal weight, and avoiding alcohol. Efforts to optimize these aspects of your health are likely to decrease your chances of developing liver or lung manifestations of Alpha-1. Patients with one and especially two copies of the Z allele are especially primed for the ill effects of a second insult, such as tobacco exposure, fatty liver disease, or alcohol.

As far as medications are concerned, there are no FDA-approved medications or vitamins indicated to treat liver disease; however there are a number of promising clinical trials currently enrolling to address this. Similarly, there are many trials currently investigating novel mechanisms to avoid the deleterious effects of the Z protein.

Given that many ZZ patients can live normal, healthy lives, I suspect that most future medications will be limited to those with at least a degree of organ dysfunction so as not to expose risk when not providing benefit, but time and trials will tell.

Q Are there other organs that are impacted by Alpha-1 besides the lung and the liver?

Alpha-1 is most commonly associated with COPD/emphysema and liver disease. Aside from COPD, Alpha-1 is also associated with other lung conditions, including asthma and bronchiectasis. Liver disease can be associated with cirrhosis, neonatal liver disease, and even liver cancer.

Outside the lungs and liver, Alpha-1 can rarely lead to a painful skin condition called panniculitis and inflammation of blood vessels called vasculitis (i.e., granulomatosis with polyangiitis). There is a possibility of association with other diseases that we have not identified to date.

Q My daughter is an MZ Alpha. What type of symptoms can an MZ Alpha experience? What testing should be done on a regular basis for MZs?

A: MZ Alphas are at risk for lung and liver disease, albeit to a lesser degree than those with ZZ. Alpha MZ itself should not lead directly to symptoms, but patients should be monitored for shortness of breath, persistent mucous production, cough, yellow eyes, leg swelling, and other lung/liver symptoms. Spirometry and blood tests for liver function can be considered for monitoring, depending on an individual's symptoms, comorbid conditions, and age.

ALPHA-1 FOUNDATION

INNOVATION 30th INSIGHT INVESTMENT 1995 2025 IMPACT

A1F RIDING FOR A REASON

SEPTEMBER 2025

#A1FRIDINGFORAREASON

Want to participate in person?

IN MEMORY OF FRED C. WALSH Alpha Angels

ESCAPE TO THE CAPE
September 26 - 28th

Join Team Alpha-1 for a one, two, or three-day Escape to the Cape bike trek in Cape Cod, Massachusetts. We are recruiting riders for the weekend to help us cross the finish line! Riders will enjoy a bike ride along the picturesque coast of the Cape. This is a fun-filled weekend with the Alpha-1 community cheering each other on and raising funds and awareness for Alpha-1.

GULF COAST BIKE TREK
October 18th

Join Team Alpha-1 in person for the 2nd Annual Gulf Coast Bike Trek in Dunedin, Florida. Choose your adventure from a seasoned cyclist's 62-mile loop, an adventure seeker's 40-mile loop, or a family-friendly trek with a 10-mile route. We're recruiting riders and volunteers for the weekend to help us cross the finish line together and raise funds and awareness for Alpha-1.

Want to participate virtually?

RIDING FOR A REASON
September - All month long

We are asking the Alpha-1 community to bike, foot pedal, or e-bike towards their personal goals during the month of September to help raise funds and awareness for Alpha-1 Antitrypsin Deficiency (Alpha-1). We will stay connected on weekly Zoom calls and by using **#A1FRidingforaReason** on social media!

Get your bikes in gear and ride as many miles as you can to help bring us closer to our mission of finding a cure for Alpha-1. Whether you are riding for yourself or in honor of a loved one, this is a great way to make a difference!

These events are open to the public and are in partnership with the American Lung Association (ALA).

Register today: ***give.alpha1.org/a1fridingforareason2025***

Keep on track with the "Good Move" activity and fundraising phone app.

Fundraising has never been so easy and as much fun!

For more information, please contact Irene Calderon at icalderon@alpha1.org

For Corporate Sponsorship information, please contact Angela McBride at amcbride@alpha1.org

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[Alpha$_1$-Proteinase Inhibitor (Human)]

For patients with emphysema caused by severe Alpha-1 antitrypsin deficiency.

No two alphas are alike.
Neither are their needs.

GLASSIA® offers the most infusion setting options; with your doctor, you can decide which works best for you.

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*If self-infusion is deemed appropriate, ensure that you receive detailed instructions and adequate training on how to infuse at home or other appropriate setting and have demonstrated the ability to independently administer GLASSIA.

Scan the code or visit glassialiquid.com to learn about which infusion setting option may be right for you.

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When you're prescribed GLASSIA, Takeda Patient Support is here for you.

What is GLASSIA?

GLASSIA is a medicine containing human Alpha$_1$-Proteinase Inhibitor (Alpha$_1$-PI) that is used to treat adults with lung disease (emphysema) because of severe Alpha$_1$-antitrypsin (Alpha$_1$) deficiency. GLASSIA is not meant to be used as a therapy for lung disease other than severe Alpha$_1$ deficiency. Effects of GLASSIA on worsening lung function and emphysema progression have not been proven in clinical trials. Long-term effects of Alpha$_1$ replacement and maintenance therapy have not been studied.

IMPORTANT SAFETY INFORMATION

What is the most important information I need to know about GLASSIA?

- GLASSIA can cause severe allergic reactions including hives, swelling in the mouth or throat, itching, tightness in the chest, trouble breathing, wheezing, faintness or low blood pressure
- If you will be taking GLASSIA outside a healthcare setting, ask your healthcare provider (HCP) about an epinephrine pen and/or other supportive care for certain severe allergic reactions.

Who should not use GLASSIA?

Do not use GLASSIA if you:

- Have immunoglobulin A (IgA) deficiency with antibodies to IgA
- Have a severe allergic reaction to human Alpha$_1$-PI products.

IMPORTANT SAFETY INFORMATION (continued)

What are the possible or reasonably likely side effects of GLASSIA?

If any of the following problems occur contact your healthcare provider (HCP) or call emergency services right away:

- Worsening or flare-up of your chronic obstructive pulmonary disease (COPD)
- Hives, swelling in the mouth or throat, itching, chest tightness, trouble breathing, wheezing, fainting or dizziness. These could be signs of a serious allergic reaction.

The most common side effects that may occur are headache and upper respiratory tract infections.

Other possible side effects of GLASSIA include:

- Cough
- Sinus infection
- Chest discomfort
- Dizziness
- Increased liver enzymes
- Shortness of breath
- Nausea
- Fatigue

These are not all the possible side effects. Tell your HCP about any side effect that bothers you or that does not go away. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see the Important Facts About GLASSIA on the next page.

Takeda

Glassia

[Alpha$_1$-Proteinase Inhibitor (Human)]

Patient Information

GLASSIA

(Alpha$_1$-Proteinase Inhibitor (Human)) Injection, For Intravenous Use

The following summarizes important information about GLASSIA (pronounced glass-see-ă). Please read it carefully before using this medicine. This information does not take the place of talking with your healthcare professional, and it does not include all of the important information about GLASSIA. If you have any questions after reading this, ask your healthcare professional.

What is the most important information that I should know about GLASSIA?

Severe allergic reactions can occur with GLASSIA. Your doctor will inform you about signs of allergic reactions which include hives, swelling in the mouth or throat, itching, tightness in the chest, trouble breathing, wheezing, faintness, low blood pressure, or serious allergic reaction.

If you have any of these reactions, discontinue use of the product and contact your physician and/or seek immediate emergency care, depending on the severity of the reaction.

If you or your caregiver will be administering GLASSIA outside a healthcare setting, ask your doctor about an epinephrine pen and/or other supportive care for certain severe allergic reactions.

Ask your doctor to make sure you receive training on how and when to use any prescribed supportive care medicine and keep it close at hand when administering GLASSIA.

What is GLASSIA?

GLASSIA is a liquid medicine containing human Alpha$_1$-Proteinase Inhibitor (Alpha$_1$-PI) also known as alpha$_1$-antitrypsin (AAT), which is purified from human blood. The main purpose of infusing GLASSIA is to increase the levels of the AAT protein in your blood and lungs. AAT protein protects the lung tissue by blocking certain enzyme-caused damage. Such damage can lead to severe lung disease, such as emphysema.

Limitations of Use:

- The effects of increasing the AAT protein levels with GLASSIA or any other Alpha$_1$-PI product on worsening pulmonary function and progression of emphysema have not been proven in clinical trials.
- The long-term effects of AAT replacement and maintenance therapy with GLASSIA have not been studied.
- GLASSIA is not intended as a therapy in individuals with lung disease other than severe Alpha$_1$-PI deficiency.

Who should not take GLASSIA?

You should not use GLASSIA if you:

- Have immunoglobulin A (IgA) deficiency with antibodies to IgA
- Have had a severe allergic reaction to human Alpha$_1$-PI products

How should I take GLASSIA?

- GLASSIA is given directly into the bloodstream.
- You can get GLASSIA at your healthcare professional's office, clinic, hospital, or delivered directly to your home by a healthcare professional from a limited network of specialty pharmacy providers.
- Your healthcare professional will decide if self-infusion in your home is right for you. You should be trained on how to do infusions by your healthcare professional.

What should I tell my healthcare professional before I start using GLASSIA?

Before starting GLASSIA, tell your healthcare professional if you:

- Have IgA deficiency with antibodies to IgA.
- Have a history of severe allergic reactions to Alpha$_1$-PI products.

What are the possible or reasonably likely side effects of GLASSIA?

- A possible side effect to GLASSIA is worsening or flare-up of your chronic obstructive pulmonary disease (COPD) in which your breathing gets worse than usual.
- Call your healthcare professional or go to your emergency department right away if you get: Hives, swelling in the mouth or throat, itching, chest tightness, trouble breathing, wheezing, fainting or dizziness. These could be signs of a serious allergic reaction.
- The most common side effects are headache and upper respiratory tract infections. Other possible side effects of GLASSIA include: cough, sinus infection, chest discomfort, dizziness, increased liver enzymes, shortness of breath, nausea, and fatigue.

These are not all of the possible side effects for GLASSIA. You can ask your healthcare professional for information that is provided to healthcare professionals. Talk to your healthcare professional about any side effects that bother you or that don't go away.

How do I store GLASSIA?

Store GLASSIA refrigerated or at room temperature.

- You can store GLASSIA in the refrigerator (36°F to 46°F [2°C to 8°C]). Do not freeze.
- You can store GLASSIA at room temperature (up to 77°F [25°C]) for up to one month. You must use GLASSIA within one month once you remove it from the refrigerator. Do not re-refrigerate GLASSIA once the product has been stored at room temperature.
- Keep the GLASSIA vial in the box until you are ready to administer the product.

Check the expiration date on the carton and vial label. Do not use GLASSIA after the expiration date.

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Partnering to Advance Our Mission

A1F works strategically with federal agencies, memberships, and coalitions—focusing on the issues that matter most to Alphas—to inform legislators of the burdens of the patient community, to advance its public policy agenda for the benefit of the Alpha-1 community, and to move its research agenda forward.

A1F is proud to partner with the American Thoracic Society (ATS) Public Advisory Roundtable (PAR) at their annual patients and experts forum. The meeting will join patient advocates and key opinion leaders from the medical community for a robust discussion. The ATS PAR is an essential part of the medical society's structure. Founded by Dr. William Martin II, former A1F board member and President of ATS at the time, the organization was envisioned "to create something quite different that would include patients at the heart of its organization."

Comprised of CEOs and other executive staff of 12-15 respiratory-related patient-interest organizations, the group works collaboratively to advance the mission of the ATS. It is a mutually beneficial relationship where collaboration advances lead to shared educational, research, and advocacy goals. PAR brings the patient perspective to the ATS and provides strategic guidance at multiple levels throughout their governance structure to keep patients as a central focus of all activities and programs. A member of PAR is appointed to various standing ATS committees, shaping policy, and stimulating research in an unparalleled synergy. PAR members meet rigorous criteria as the group brings the patient voice to all ATS work, including the ATS International Conference. PAR members serve a volunteer term of three years.

Jon Hagstrom, Chair of the A1F Board of Directors, is currently a member of PAR. As a ZZ Alpha-1 patient and bilateral lung transplant recipient, Jon is an ideal member for this roundtable. Jon serves in a variety of roles for the Foundation, spanning all aspects of our mission. He is a fierce advocate for fellow Alphas, actively lobbying Congress for better care, championing patient interests to the FDA, and promoting early detection.

> I'm proud to be able to add Alpha-1 to the many patient voices represented on the ATS Public Advisory Roundtable. The PAR brings patient perspectives to the highest levels of respiratory health discourse, and it is important to add the unique challenges of the Alpha-1 community to the mix.
>
> —**Jon Hagstrom**
> **Chair of the Alpha-1 Foundation Board of Directors**

A1F also partners on an annual matching research grant with ATS titled ATS/A1F Young Investigator Grant in Alpha-1 and is targeted to support early-career investigators who are starting their research careers and intend to pursue a career in Alpha-1 research. Applications are invited from candidates holding an MD, PhD, or equivalent degree who are interested in conducting basic science, clinical research, or studies on ethical, legal, or social issues related to Alpha-1.

A1F Memberships and Coalitions

A1F works collaboratively through its memberships and coalitions to ensure the Alpha-1 patient is represented on all issues. Policy priorities include Alpha-1 medical research, therapeutic development, screening and detection, access to care, federal and state funding, blood product safety, and education and awareness. A1F fosters and maintains ongoing relationships with like-minded health organizations, working with key partners to amplify the voice of the patient.

ALPHA-1 FOUNDATION

Clinical Trials Education

Interested in better understanding how a drug comes to fruition?

Through the Clinical Trials Education Program, you can learn more about different phases and types of clinical trials, how inclusion/exclusion criteria can affect participation in a study, what is informed consent and why it is important, and the next steps to get involved!

For more information, visit:

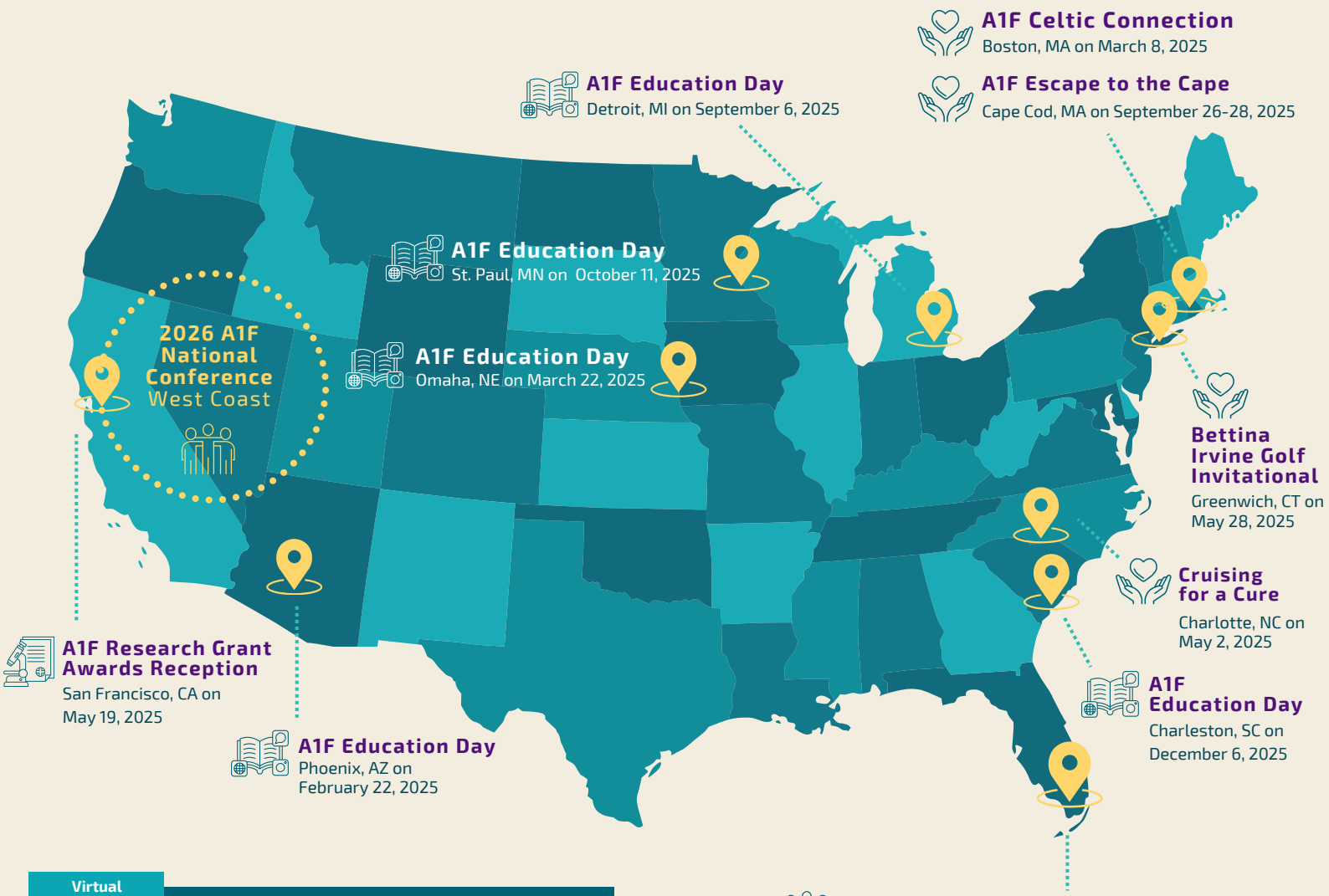
www.alpha1.org/clinical-trials-101

The Redwood Study is looking for adults 18 to 75 years of age who have a confirmed or suspected diagnosis of Alpha-1 Liver Disease with PiZZ genotype. There is currently no approved treatment available for Alpha-1 Liver Disease. The investigational study drug aims to reduce the production of the abnormal Z-AAT protein and its buildup in the liver. To learn more and see if you may qualify, talk to your doctor and visit **alpha1.org/redwood-study-prescreening/** today.

The Redwood Study

ALPHA-1 FOUNDATION

2025 Major Meetings & Events



Virtual

VIRTUAL

The Virtual Alpha-1 Foundation Education Day & State of the Union will take place January 22, 2025.

Alpha-1 Global

PORTUGAL

The Alpha-1 Global 7th Research Conference & 10th Patient Congress will take place April 4-5, 2025, in Portugal.

Netherlands

The 2025 Clinical Trials Roundtable at EASL Congress will be held in Amsterdam on May 7 - 10, 2025.

Alpha-1 Foundation National Conference
Miami, FL on June 6 - 8, 2025

Alpha-1 Leadership Meetings
Miami, FL in October 2025

28th Gordon L. Snider (GLS) Critical Issues Workshop
Miami, FL in October 2025

To learn more about all Alpha-1 Foundation events in 2025, including virtual events and initiatives, visit: alpha1.org/calendar

Dates may be changed at the discretion of A1F.

Calendar of Events 2025

Are you receiving our emails?

Do you receive the monthly e-newsletter “Community Currents”? This is a good time to check that you are on our e-mail list. Update your contact information by visiting alpha1.org.

For additional support group meetings, please check the calendar of events on **alpha1.org/calendar**

A1F Support Group Meetings

May 24, 2025
Georgia Alphas
Johns Creek, GA

June 22, 2025
Idaho Alpha-1 Community Outreach
Meridian, ID

July 27, 2025
Hoosier Support Group
Indianapolis, IN

A1F Education Events

September 2, 2025
Detroit A1F Education Day
Detroit, MI

October 11, 2025
St. Paul A1F Education Day
St. Paul, MN

December 6, 2025
Charleston A1F Education Day
Charleston, SC

A1F Upcoming Events

May 29, 2025
Bettina B. Irvine Invitational Classic
Greenwich, CT

May-August 2025
Ice Cream for Alpha-1 BFC Fundraisers

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ALPHA-1 FOUNDATION

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Do you receive Alpha-1 Foundation email blasts, event reminders, or fundraising updates?

Be sure to update your e-mail address and contact information by visiting:

alpha1.org/subscribe