



1 ALPHA-1
FOUNDATION

PROGRAM REPORT 2022

Our Mission

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

The Alpha-1 Foundation is dedicated to finding a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1) and is tirelessly improving patient care along the way. Our initiatives in four main areas—Research, Education/Outreach, Awareness/Fundraising, and Public Policy/Advocacy—are paving the way for important discoveries, new therapies, and increased awareness and understanding of this rare genetic condition.


We work to combat Alpha-1 at its earliest stages by supporting programs that push the boundaries of existing data, detection, and patient support. Our accomplishments and accreditations reflect our unparalleled commitment to medical research at its finest: we have invested over \$90 million to support Alpha-1 research and programs at 128 institutions in North America, Europe, South America, the Middle East, and Australia. These innovative, impactful projects have built a solid infrastructure for promoting ongoing research and the development of new therapies. We have also fostered collaborations with investigators throughout the United States and Europe, working closely with the pharmaceutical industry, the National Institutes of Health (NIH), the U.S. Food and Drug Administration (FDA), and Alpha-1 patients and families.

Our work would not be possible without our dynamic community of volunteers, researchers, clinicians, partners, and donors—all of whom inspire and empower us every day in our mission to raise awareness and deliver results for those affected by Alpha-1. We are incredibly grateful to our global network of specialists, which spans multiple industries, areas of research, and academic expertise. It is thanks to these innovative and patient-centric groups that we are driving real, positive change.

We sincerely thank you for your support as we continue to improve the treatment, quality of life, and outcomes for all Alphas while working toward a cure.

Table of Contents

Research & Science //////////////////////////////////////	4
Alpha-1 Research Registry	5
Clinical Resource Centers (CRCs)	6
Therapeutic Development Network (TDN)	7
Research Grants and Awards	8
Alpha-1 Coded Testing (ACT) Study & Detection	10
Alpha-1 Biomarkers Consortium (A1BC)	11
Alpha-1 Research Biorepositories	12
Conferences and Forums	13
Education & Outreach //////////////////////////////////////	14
Alpha-1 National Conference	15
Alpha-1 National Education Series	16
Professional Education	17
Educational Resources	18
www.alpha1.org	19
<i>Alpha-1-To-One</i> Magazine	20
E-Education Library	21
Educational Brochures	22
Community Currents Newsletter	22
<i>Alpha-1-To-One</i> Podcast	23
Patient Outreach	24
Patient Support Network	25
Genetic Counseling Program	26
Alpha-1 Kids	27
Educational Scholarships	28
Awareness & Fundraising //////////////////////////////////////	29
Building Friends for a Cure (BFC)	30
Alpha-1 Awareness	31
Special Events	31
Public Policy & Advocacy //////////////////////////////////////	32
Advocates in Action	33
Alpha-1 Global	35



Accelerating research toward a cure for Alpha-1

We take a comprehensive, big-picture approach to research, from funding targeted, high-impact programs to advancing the Alpha-1 research field.

Alpha-1 Research Registry

Facilitating participation in research studies and clinical trials for new treatments and therapies



The Alpha-1 Research Registry, comprised of both patient-supported data and clinical data, has become an invaluable resource for the Alpha-1 community. Since its update in 2019, it has served as a solution to one of the most significant barriers slowing Alpha-1 research – the difficulty locating patients living with or impacted by this rare condition to participate in research studies. The Alpha-1 Research Registry plays a pivotal role in the Alpha-1 Biomarkers Consortium (A1BC) Study and is the foundation of data collection for the Therapeutic Development Network (TDN).

We recruited over 550 Alphas and family members to the Alpha-1 Research Registry in FY 2022, bringing the total number of Registry participants to 2,800.

**SPOTLIGHT:
Looking Ahead**

Alpha-1 Research Registry

As the number of stakeholders referencing the Alpha-1 Research Registry continues to grow, we are working to increase enrollment and expand access to data available to advance the field and accelerate progress.

Clinical Resource Centers (CRCs)

A growing network of research institutions and physicians specializing in Alpha-1 treatment, education, and care



**An Expansive
Network of
Alpha-1 Specialists
and Research
Institutions**

77
CRC Sites in the
U.S. and Canada

87
CRC Physicians

Designated Clinical Resource Centers (CRCs) provide comprehensive care to Alphas, including specialized care for lung disease and liver disease. CRCs play a critical role in helping the Foundation recruit patients for the Alpha-1 Research Registry. In addition, CRCs provide patients the resources and information needed to manage their Alpha-1.

All CRCs go through a rigorous designation process and are required to adhere to the highest standard of care and best practices.

We are excited to announce our newest CRCs and updated leadership:

The Ohio State Wexner Medical Center | Columbus, Ohio
Jing (Gennie) Wang, MD

Pulmonary & Sleep of Tampa Bay | Tampa, Florida
Dragos Zanchi, MD, FCCP

SUNY Upstate Medical University | Syracuse, New York
Auyon J. Ghosh, MD, MPH

Therapeutic Development Network (TDN)

Connecting the top specialists and industry partners to accelerate the development of novel treatments for Alpha-1



The Therapeutic Development Network (TDN) is a clinical trial platform through which leading Alpha-1 specialists, researchers, and biopharma partners work to improve trial recruitment and design advanced patient-focused drug development programs. The TDN leverages the Alpha-1 Research Registry and our extensive network of CRCs to help industry partners with clinical trial recruitment and site selection.



SPOTLIGHT: **Looking Ahead**

CRCs & the TDN

Research is a cornerstone of our mission and, as the primary networks through which investigators connect with Alphas, CRCs and the TDN are essential components of promoting and facilitating clinical trials and research studies. Our goals for the future include:

- Increase the number of CRCs focused on liver disease
- Increase patient participation in clinical trials
- Market clinical trials through CRCs to improve participation
- Develop a CRC Mentorship Program

Research Grants and Awards

Sponsoring research into lung and liver disease, as well as ethical, legal, and social issues impacting people with genetic conditions

The Alpha-1 Foundation directed more than \$2 million in peer-reviewed research grants in FY 2022. These grants support innovative research spanning the spectrum of scientific discovery.

World's #1 Funder of Alpha-1 Research Support

- We've invested over \$90 million in Alpha-1 Research
- We've funded 128 institutions in 14 countries worldwide

Advancing the Next Alpha-1 Breakthrough

Research funded by the Alpha-1 Foundation has improved understanding of the mechanisms underlying the clinical manifestations of Alpha-1 and identified novel drug targets likely to lead to new therapeutic solutions.

2021-2022 Grant Recipients

Postdoctoral Research Fellowship

Committing \$75,000/year over a two-year period

Shah Hussain, PhD

University of Alabama at Birmingham
Severity and progression of airway dropout in AAT knockout transgenic ferret model of COPD

Georgios Sophocleous, PhD

University College London
Structural and biophysical dissection of the alpha-1 antitrypsin polymerisation pathway

Francesco Annunziata, PhD

Telethon Institute of Genetics And Medicine (TIGEM), Naples
Identification and modulation of local and systemic environmental factors in AATD

Research Grants

Committing \$100,000/year over a two-year period

Valerie Gouon-Evans, PhD

Boston Medical Center
Engineered and edited patient-derived iPSC for AATD-associated liver disease cell therapy

Pasquale Piccolo, PhD

Telethon Institute of Genetics and Medicine
Mitochondrial dysfunction in a1-antitrypsin deficiency-associated liver disease

Tomás Carroll, PhD

Royal College of Surgeons in Ireland
A Family Affair - Clarifying the Risk of Lung Disease in ZZ AATD

Lisa Cabrita, PhD

University College London
Modulating the co-translational misfolding and polymerisation of antitrypsin

Brian Hobb, MD

Brigham and Women’s Hospital
Inflammatory Protein Biomarkers of Reduced Lung Function in AATD

Joseph Kaserman, MD

Boston University
Mechanisms of Hepatic Heterogeneity and ATF6 Mediated Metabolic Dysfunction in AATD

Monica Goldklang, MD

Columbia University Irving Medical Center
Longitudinal evaluation of lung disease progression in PiMZ patients

Jarrett Morrow, PhD

Brigham and Women’s Hospital
Blood and lung microbiome in alpha-1 antitrypsin deficiency

John W. Walsh Translational Research Award in Alpha-1 Antitrypsin Deficiency

\$250,000/year over three-year period in honor of John W. Walsh, co-founder and past President & CEO of the Alpha-1 Foundation

Nazli Khodayari, PhD

University of Florida
Novel Biomarkers for Alpha-1-Antitrypsin Mediated Liver Disease in Circulating Exosomes

Matching Grants/Awards

\$25,000 grants provided in partnership with the American Thoracic Society, American College of Chest Physicians Foundation, American Association for the Study of Liver Diseases, American Lung Association, American Association for Respiratory Care, and the National Institutes of Health, among others.

Alpha-1 Foundation/CHEST Foundation Clinical Research Award in COPD and Alpha-1

John Rotondo, PhD

University of Ferrara, Italy
Alpha-1 antitrypsin protein (AAT) as a possible marker of disease progression in COVID-19 patients



Research Grant funding supports the work of Jeffrey Teckman, MD, at St. Louis University, to better

understand the clinical implications of liver disease in Alpha-1 patients.

Dr. Teckman’s research with the Alpha-1 Liver Initiative focuses on adult Alphas, and his work with the Childhood Liver Disease Research and Education Network (ChiLDREN) focuses on rare pediatric liver disease. In 2022, Dr. Teckman’s work alongside industry partners, and with A1F funding, led to the discovery of a potential treatment for liver disease associated with Alpha-1.

Alpha-1 Coded Testing (ACT) Study & Detection

A research study investigating perceived risks and benefits of genetic testing in Alpha-1 families, disease-specific risks, and co-morbidities for Alpha-1

The Alpha-1 Coded Testing (ACT) Study is a confidential testing program aimed at those who are at risk of Alpha-1. The ACT Study provides an opportunity for individuals and their family members to be tested for Alpha-1 in the privacy of their homes, without concern for health and life insurance issues associated with a diagnosed pre-existing condition.

The ACT Study also offers Alpha-1 families the opportunity to be part of research aimed at better understanding population demographics, testing attitudes and behaviors, and clinical outcomes among those at risk for Alpha-1. The study has already yielded valuable insights—5.0% of those tested were diagnosed ZZ Alphas, and 52% of those tested were identified as carriers of Alpha-1.



The ACT Study has enrolled—and screened—almost 10,000 individuals, with 1,897 participating in FY 2022 alone.

Alpha-1 Biomarkers Consortium (A1BC)

Studying disease indicators to identify at-risk patients and determine early interventions



The Alpha-1 Biomarkers Consortium (A1BC) aims to identify biomarkers that could be used to study the clinical progression of disease and could inform the design of future clinical trials. Led by Principal Investigator Jeanine D'Armiento, MD, PhD, Columbia University, the A1BC is conducting a six-year study that taps the Alpha-1 Research Registry to identify unaddressed research questions in Alpha-1 and clinically-relevant outcomes. Research participants will be followed over a three-year period to investigate a series of serum and imaging biomarkers. Patient-reported data will be collected through questionnaires.

The A1BC study is funded through the multi-center grant from the National Institutes of Health (NIH) and supplemented by funding from Alpha-1 Foundation.

SPOTLIGHT: **Looking Ahead**

ACT & A1BC

We are conducting an environmental scan of Alpha-1 testing for cost, and test results turnaround time, with the goal to improve Alpha-1 testing availability and efficacy to strengthen diagnostics and response.

Data and materials collected in the A1BC will be transferred to the Alpha-1 Research Registry when the study concludes. These additions will enhance the Alpha-1 Research Registry and provide additional data to analyze the natural history of Alpha-1 and support better, more efficient recruitment for studies.

Alpha-1 Research Biorepositories

Providing Alpha-1 researchers from around the world with difficult to obtain DNA, plasma, lung tissue and liver tissue donated from Alphas, as well as supplementary biomaterial samples, to advance research

The Alpha-1 **DNA and Tissue Bank** contains de-identified clinical information and DNA and plasma samples from 2,572 Alphas. It is accessible to researchers in academia, government, and industry whose applications are approved by the Foundation's DNA & Tissue Bank Advisory Committee.

The Alpha-1 **Biomaterials Exchange** is a resource for both industry and academia that matches an investigator in need of biomaterial with another investigator who is a supplier of biomaterial. Importantly, the Biomaterials Exchange includes biomaterials not included in the DNA and Tissue Bank, such as viruses, viral vectors, plasmids, mice, and cell lines.



Conferences and Forums

Generating awareness of Alpha-1, identifying new areas of research interest, and establishing the Foundation's credibility within the rare disease community as a resource for serious research, education, and advocacy

Gordon L. Snider (GLS) Critical Issues Workshop Series

The GLS Workshop series facilitates exchanges between experts and answers important questions to stimulate additional research. Three recent workshops focused on liver biomarkers, CT lung densitometry, and the promise of gene-based interventions in Alpha-1.

Clinical Resource Center (CRCs) Forums

These forums serve as platforms for networking, planning, and collaboration among CRCs, researchers, and industry partners.

We reach thousands of physicians, academic researchers, and industry partners each year through our exhibitions at major national and international medical conferences, where we share insights into new technologies, research findings, and priority research areas.

The Alpha-1 Foundation exhibits at:

- European Respiratory Society (ERS) International Congress
- American Association for the Study of Liver Diseases (AASLD) Meeting
- American Association for Respiratory Care (AARC) Congress
- National Institutes of Health (NIH) Rare Disease Day
- American Thoracic Society (ATS) International Conference



Empowering the Alpha-1 community with educational resources and direct support

The more we understand about Alpha-1, the better equipped we are to treat it. As we work toward a cure, empowering the Alpha-1 community is our priority.

IMPACT: EMPOWERING PATIENTS TO MAKE INFORMED DECISIONS ABOUT THEIR CARE AND TAKE PART IN ALPHA-1 RESEARCH

Alpha-1 National Conference

Bringing the Alpha-1 community together in the search for a cure



1,195
registered to attend
the 2022 Alpha-1
National Conference

667
attended from
47 states and 10
countries

510
patients and family
members

53
medical
professionals

23%
in attendance joined
for the first time

As the largest annual gathering of the Alpha-1 community, the National Conference provides important opportunities for networking, education, advocacy, and industry publicity. Over the course of four days, attendees have access to scientific presentations, meet-and-greet and Q&A sessions with Alpha-1 experts, and other events hosted by sponsors.

Alpha-1 National Education Series

Bringing patient education to a regional audience

The Alpha-1 National Education Series is comprised of Alpha-1 Education Days for Alphas, their families, and caregivers. These one-day educational programs provide access to current medical information, timely topics affecting Alphas, resources from leading Alpha-1 experts, and opportunities to connect with the Alpha-1 community.

Alpha-1 Education Days are held across the U.S., either in collaboration with a CRC or in a specific underserved area. Local Support Group Leaders and Alphas are engaged in regional planning committees and design programming according to the specific interests and needs of the Alphas in the region they serve, with a focus on connecting people to local resources. The American Association of Respiratory Care (AARC) has approved continuing education hours for respiratory therapists in attendance.

In 2022, the Foundation continued its use of a virtual event platform, enabling those who were unable to attend an Alpha-1 Education Day in-person to participate and connect with the Alpha-1 community. Extending our Education Series into the virtual space has also created community-building and engagement opportunities through more direct access to social media, polls, and surveys.



2,323
people registered
for the FY 2022
Virtual Alpha-1
Education Days.

SPOTLIGHT: **Looking Ahead**

Alpha-1 National Conference and Education Series

We are making our way back to in-person events with an eye toward increasing engagement in the Alpha-1 National Conference and Alpha-1 Education Series. We are planning targeted marketing and communications campaigns around enrollment in these events, and embracing a hybrid online/in-person structure to ensure access for the greater Alpha-1 community.

Professional Education

Filling gaps in education for healthcare providers and improving understanding of Alpha-1 within the medical community

The Alpha-1 Foundation, in partnership with professional organizations, offers opportunities for continuing education credits on a range of topics related to Alpha-1, including diagnosis, testing, augmentation therapy and treatment.

We offer a free online course providing one contact hour for registered nurses and nurse practitioners. We also identify opportunities for virtual and in-person Grand Rounds and encourage CRC physicians to present on research and new therapies.

More than 95 medical providers have completed the Nurse Practitioner Continuing Education credits through the Professional Education program, including 21 in FY 2022.

More than 710 medical providers have completed the Respiratory Therapist Continuing Education credits through the Professional Education program since inception, including 45 in FY 2022.

Partner Organizations

- Association for Continuing Education (NACE)
- Nurse Practitioner Associates for Continuing Education (NPACE)
- National Association of Pediatric Nurse Practitioners (NAPNP)
- American Association of Nurse Practitioners (AANP)
- American Association for Respiratory Care (AARC)

SPOTLIGHT: **Looking Ahead**

Professional Education

We are working to expand our Continuing Medical Education Program and continuing to build the Professional Education mechanism within our CRCs. One goal of our focus on Grand Rounds is to incorporate standard Alpha-1 testing for all patients with COPD into physician practice.

We are partnering with the Cleveland Clinic to create a new healthcare professional medical education series, which will target 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.

Educational Resources

The background of the page is a blurred photograph of a group of people, likely in a classroom or meeting room. They are all wearing light blue surgical face masks. The image is overlaid with a semi-transparent purple filter. The text is positioned in the upper left and lower right areas.

We offer a suite of educational resources designed to increase access and understanding, enhance community engagement, and promote best practices related to Alpha-1 testing, diagnosis, and care.

www.alpha1.org

A clearinghouse for information on Alpha-1

Our website provides educational resources, highlights news and upcoming events, and creates opportunities for virtual connection within the global Alpha-1 community. We maintain content targeted toward several different audiences, including newly diagnosed Alphas, family members and caregivers, healthcare providers, researchers and industry partners.

Alphas and their families visit our website to access educational content, build connections with others in the Alpha-1 community, and find a CRC specialist or local support group. Healthcare providers visiting our website can find guidelines on diagnosing and treating Alpha-1, as well as links to specialists for referrals, while researchers can find information on funding opportunities.

www.alpha1.org received 484,173 visits from 234,737 unique visitors in FY 2022

Most Visited Pages

What is Alpha-1? (85,880 visits)	Newly Diagnosed/ Liver Disease (19,803 visits)
Home Page (83,174 visits)	
Testing for Alpha-1 (28,408 visits)	Newly Diagnosed/ Lung Disease (18,200 visits)
COVID-19 (24,282 visits)	

SPOTLIGHT: Looking Ahead

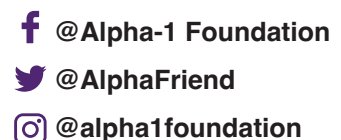
www.alpha1.org

We are undertaking a redesign of our website to provide a more tailored, user-friendly, interactive experience, featuring:

- Accessible content
- Focused Calls to Action
- Direct communication (Web Chat)
- Interactive infographics and animation
- Improved SEO and search rankings
- Media library module

Follow Us Online!

We connect with the Alpha-1 community across multiple social media channels. In addition to promoting new Foundation initiatives, community education events, and fundraising campaigns, our presence on Facebook, Instagram, and Twitter has directly increased traffic to our website, where users can access the information they need.

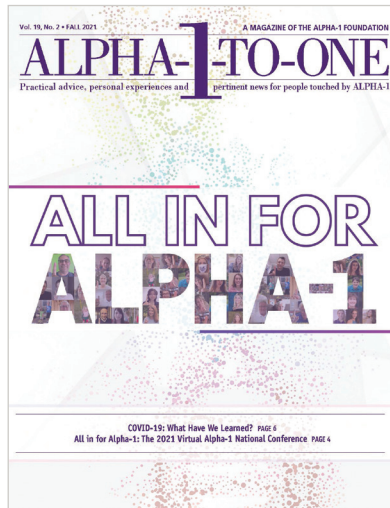


Alpha-1-To-One Magazine

A seasonal magazine providing practical advice, patient stories, and pertinent news to the Alpha-1 community



Spring 2022



Fall 2021



Winter 2021

The *Alpha-1-To-One* Magazine is a valued resource for the Alpha-1 community; most readers identify as Alphas, family and caregivers. Other audiences of the magazine include medical professionals, researchers, and donors.

In FY 2022, we distributed 30,000 printed copies of each *Alpha-1-To-One* issue, including bundles to CRCs and healthcare providers; each issue is posted to a digital publishing platform on our website, where it was accessed by nearly 2,000 more visitors this year.

Each issue of *Alpha-1-To-One*, published tri-annually, includes research updates, an introduction to Alpha-1 specialists and researchers, and a recap of our outreach and advocacy efforts. Additional content is determined by an editorial board of patients, physicians and researchers, and other supporters, based on new and emerging needs of the Alpha-1 community.

In response to a survey in the Spring 2021 issue, subscribers identified the magazine as “informative” and

over 70% reported using the links provided

throughout the magazine to seek additional information.

E-Education Library

Alpha-1 related content—anywhere, anytime, on any device

We added more than 60 educational presentations to the E-Education Library during FY 2022. The library, which can be accessed via our website, includes more than 600 presentations from our educational events, including Alpha-1 Education Days and Alpha-1 National Conferences. It has become a valuable resource for the global Alpha-1 community and is frequently used by Alpha-1 support group leaders as a tool to offer expert presentations at meetings.

We add content to the E-Education Library throughout the year, with new videos promoted through e-mail, social channels, and our website. With presentations ranging from “Clinical Trials Explained & How a Therapy Comes to Market” to “Pulmonary Rehab Webinar: Exercises You Can Do at Home,” the library offers useful content for everyone in the Alpha-1 community.

E-Education Library Topics

- Advocacy
- Caregiving
- Children and Alpha-1
- Genetics
- Getting involved
- Liver
- Living with Alpha-1
- Lung
- Nutrition
- Oxygen
- Pulmonary rehab and exercise
- Research
- Transplantation

IMPACT: EMPOWERING PATIENTS TO MAKE INFORMED DECISIONS ABOUT THEIR CARE AND TAKE PART IN ALPHA-1 RESEARCH

Educational Brochures

Medically validated brochures to help the Alpha-1 community stay informed

We distributed more than 13,800 printed brochures in FY 2022 to numerous audiences, including Alpha-1 patients and families, healthcare professionals, and those at risk of Alpha-1.

Brochures are disseminated to: CRCs, Alpha-1 support group leaders, AlphaNet Coordinators, attendees at meetings and conferences, and inside test kits sent from the ACT Study. Brochures can also be downloaded or requested on our website and by calling or emailing the Foundation.

Brochure Topics

- Healthcare Providers Guide
- How to Find an Alpha Doc
- What is Alpha-1?
- It's All in the Family - Family Testing
- The Liver and Alpha-1
- Am I an Alpha-1 Carrier?
- A Guide for the Recently Diagnosed Individual
- Clinical Trials
- Research Opportunities

IMPACT: CONNECTING AND STRENGTHENING THE ALPHA-1 COMMUNITY

Community Currents Newsletter

Monthly e-newsletter highlighting current Foundation initiatives and opportunities for involvement

Our Community Currents e-newsletter provides timely updates on upcoming programs and events, fundraising activities, and research efforts, such as the Alpha-1 Research Registry.

Alpha-1-To-One Podcast

An opportunity for listeners to experience portions of the *Alpha-1-to-One Magazine* in an audio format

The *Alpha-1-To-One Podcast*, hosted by Alpha Richard Lovrich, tells the personal stories of Alphas, families, healthcare providers, researchers, and other members of the Alpha-1 community. Grounded in the readership of the *Alpha-1-To-One Magazine*, the podcast expands the Foundation's media platform to an audio medium that has the capacity to reach a new audience, including the next generation of the Alpha-1 community.

We work closely with the Alpha-1 community to determine content for podcast episodes while building listenership and engagement.



SPOTLIGHT: Looking Ahead

Educational Resources

We are always looking for new ways to reach Alphas, increase community engagement, and inform patient care. As we embark on a redesign of our website, we are simultaneously building consistent, identifiable branding into our digital and print materials to strengthen the Foundation's identity. Our goal is to provide innovative content packaged in a familiar form.

Patient Outreach



Our programs help Alphas get answers to critical questions, access expert care, and stay informed about Alpha-1 treatment options and clinical trials—supporting patients with information and resources to improve their lives.

Patient Support Network

Providing support and education to Alphas and family members and creating awareness of Alpha-1 in local communities



We manage a Patient Support Network of 80 affiliate support groups, approximately half of which hold monthly meetings. The Patient Support Network is designed to foster an enhanced, healthy sense of identity and connection with the larger Alpha-1 community while extending the Alpha-1 Foundation's mission to local communities. Support group leaders receive education and training throughout the year, with many serving as advocacy ambassadors in regions with a local CRC. Support group leaders work with physicians and CRC staff to organize coordinated community education and awareness events and assist in the planning of Alpha-1 Education Days.

Direct Patient Support

Patient Information Line

In FY 2022, the Patient Information Line fielded 699 calls, helping Alphas and family members locate specialists, access support, and gain information on a range of topics, including managing Alpha-1, COVID-19 risks, and understanding Alpha-1 testing.

Emergency Relief Fund

The Emergency Relief Fund is a collaboration between the Alpha-1 Foundation and the National Organization for Rare Disorders (NORD) that provides financial assistance to Alphas and their families. Support of up to \$500 can be used to pay for basic and urgent needs outside of insurance premiums or co-payments. In FY 2022, 82 Alphas and their families received support from this program.

Oxygen Travel Assistance Program

The Alpha-1 Foundation's Oxygen Travel Assistance Program provides access to supplemental oxygen systems to support Alphas traveling for medical emergencies, transplant evaluation, and visits to CRCs. In FY 2022, we loaned and facilitated the delivery of 8 supplemental oxygen systems to Alphas in need.

CRC Access Program

Patients can apply for a one-time travel stipend of up to \$500 to visit their nearest CRC for the first time. The CRC Access Program supports access to Alpha-1 specialists who provide can provide best-practice health management strategies and discuss augmentation therapy.

Genetic Counseling Program

Helping Alphas understand their diagnosis by providing psychological, medical, and familial support



We partner with the University of Florida to provide free genetic counseling services to Alphas, family members, healthcare providers, and other individuals considering testing or in need of support. The Genetic Counseling Program is invaluable in helping patients understand their genetic risk for developing lung and liver disease, as well as communicating that information to family members.

Trained counselors field calls for personalized genetic counseling, interpreting results from ACT Study participants, and referrals based on specific need. Many callers are newly diagnosed Alphas looking for initial information and recommendations.

It's All in the Family — Family Testing

We feature family testing material at select Alpha-1 Education Days and Clinical Resource Centers, and distribute a series of communications to engage Alphas in this important detection program, including the *It's All in the Family* brochure and newsletter features on Family Testing.

SPOTLIGHT: Looking Ahead

It's All in the Family and the Genetic Counseling Program

We are positioning ourselves to improve Alpha-1 detection and expand patient services, using the virtual network we've established during the last two years as a framework for communications and program promotion to help Alphas get the care they need—sooner.

Alpha-1 Kids Program

Information and resources for families of Alpha-1 infants, children, and teens, as well as young adults transitioning to independent care

People under 25 years old are underrepresented in Alpha-1 demographic data. We recognize that the unique needs of this population require focused support and are working closely with the Alpha-1 community to identify gaps and new areas of program expansion. The Parents of Alpha-1 Kids (PAK) virtual Support Group provides specialized resources for families who are looking for support during their child's Alpha-1 journey.

“My goal for the PAK is to provide a community for parents and caregivers to come together and share their experiences, hopes and worries. In a world filled with so much information, it is critical to provide a safe space to share credible information and resources about Alpha-1. Providing hope and encouragement to travel this road together will allow Alpha-1 to be a part of our stories, not the center of our lives.”

— Erin Carr, PAK Support Group Leader and Alpha Mom



Educational Scholarships

Funding educational opportunities for those impacted by Alpha-1

We award educational scholarships to Alphas and family members seeking to further their education at an accredited university, college, community college, or technical institute. In FY 2022, 8 Alpha-1 Educational Scholarships, totaling \$20,000, were awarded.

James Quill Memorial Scholarships

Althea Pleasants, from Powell, Ohio, is an incoming freshman at Ohio Northern University.

Morgan Vajdos, originally from Galveston, Texas, is a senior at the University of Texas Medical Branch in Galveston, majoring in Nursing.

Robert J. Haggerty Memorial Scholarship

Cecelia Bohn, from Plano, Texas, is a junior at the Ohio State University majoring in Nursing.

John W. Walsh, III (Jack) Memorial Scholarship

Chase Castillo, from San Antonio, Texas, is a freshman at Arizona State University majoring in Professional Flight.

E. Lou Glenn Memorial Scholarship

Monica Beck, from Upton, Kentucky, is a junior at the University of Louisville, majoring in Nursing.



Terry L. Young Memorial Scholarship

Eli Grimm, from Boulder, Colorado, is a junior at the University of Colorado Boulder, double majoring in Sociology and Public Relations.

Peter Smith Scholarships

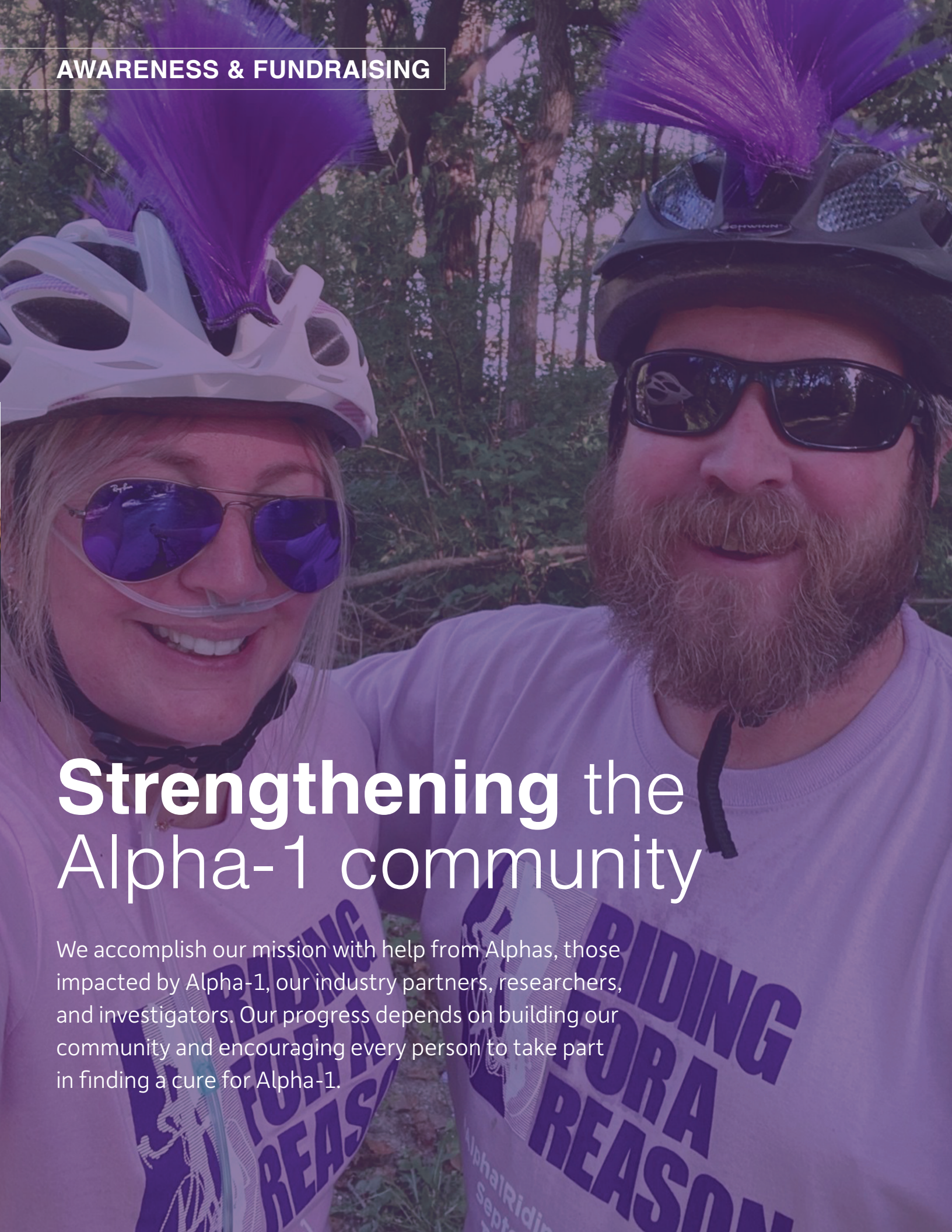
Katelyn Keeler, from Cement City, Michigan, is a freshman at Taylor University, majoring in Engineering.

Nancy Parham, from Bullhead City, Arizona, is enrolled in the Family Nurse Practitioner Program at the University of Phoenix.

AWARENESS & FUNDRAISING

Strengthening the Alpha-1 community

We accomplish our mission with help from Alphas, those impacted by Alpha-1, our industry partners, researchers, and investigators. Our progress depends on building our community and encouraging every person to take part in finding a cure for Alpha-1.



Building Friends for a Cure (BFC)

Community fundraising programs designed to increase awareness and promote research



Support from the Alpha-1 community is a critical component of our goal to raise awareness of the disease and treatment options. Through the Building Friends for a Cure (BFC) program, we steward relationships with donors to boost awareness of Alpha-1 and get the community involved in working toward a cure.

In the last year, Alphas, friends and family, researchers, industry and medical professionals came together to raise funds for research for a cure for Alpha-1. Some of this year's activities included successful social network campaigns and the utilization of online fundraising platforms. For example, during a recent Alpha-1 Virtual Walk, 700 participants tracked miles on STRAVA and raised over \$72,000 for Alpha-1 in just one month.



Building Friend for a Cure consists of a series of community fundraising events in support of Alpha-1 research, including:

- Riding for a Reason
- Escape to the Cape
- Alpha-1 Virtual Walks
- Celtic Connection
- Walks, runs and marathons
- Alpha Hours
- Climbs and hikes
- Video game streaming

SPOTLIGHT: Looking Ahead

Building Friends for a Cure

We are actively working to build and re-engage the community and increase participation in the BFC program. Our goal is to continue using the virtual platform we have built over the last two years to reach a wider audience and provide both virtual and in-person opportunities for Alphas worldwide to get involved in the search for a cure.

Alpha-1 Awareness

Annual campaigns to facilitate community support and improved approaches to care

Content created for Alpha-1 awareness campaigns appears in programming throughout the year.

#Alpha1Awareness

November is Alpha-1 Awareness Month—30 days of awareness-focused initiatives, through which the Alpha-1 community shares stories and resources while raising funds to support the search for a cure.

#SHOWYOURSTRIPES

During month of February, we collaborate with the National Organization for Rare Disorders (NORD) to spread awareness of Alpha-1 for Rare Disease Day. The goal: to get patients interested and involved in rare disease research.



Special Events

Celebrating the Alpha-1 community and supporting research

Our Special Events are opportunities to expand our donor and volunteer base and raise funds for programs and research. Over 300 guests attended the following Special Events in FY 2022:

Alpha-1 Foundation Grant Awardees Reception: Alphas, physicians, researchers, and industry partners attended the virtual reception to recognize newly awarded grantees for their work in Alpha-1 and their role in the search for a cure.

Celebration of Life: This annual golf tournament and reception benefits transformative Alpha-1 research and advances our mission to find a cure. Attendees include Alphas, family members, senior leadership, and industry representatives. This year the event was held in Greenwich, Connecticut, as the Bettina Irvine Invitational.

Generating change to improve outcomes for Alpha-1 patients

Alpha-1 is a rare condition and is underrecognized, underdiagnosed, and unknown to most people. We are fighting to change that by ensuring our community's priorities are factored into public policy around the world.



Advocates in Action

Advocating for the Alpha-1 community by monitoring and influencing legislative and regulatory issues



Our advocacy program targets policymakers, regulatory agencies, the public, and the media with campaigns to promote research and raise awareness of the challenges faced by Alpha-1 patients and care providers. Our public policy work is carried out in part by our grassroots community as well as by key stakeholders, staff, and our extensive network of healthcare professionals. The Foundation provides training, guidance, and resources to empower, educate, and mobilize Alphas to convey the urgency of our cause.

Advocates urge members of Congress and federal agencies to prioritize the needs of Alphas and those affected by rare and chronic conditions, with a focus on eliminating barriers to healthcare coverage, advocating for telehealth and home infusion, ensuring access to essential medications and therapies, raising awareness of patient needs, and improving patient detection and outcomes. Alpha-1 advocates represent the Alpha-1 Foundation at forums and lobby days each year.

Policy priorities include:

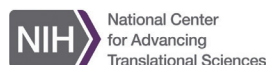
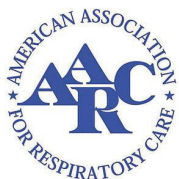
- Medical research
- Therapeutic development
- Screening and detection
- Access to care
- Federal and state funding
- Blood product safety
- Education and awareness

Institutional, Agency, and Coalition Partners

The Foundation 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 and to advance our public policy agenda for the benefit of the Alpha-1 community.

- **U.S. Food and Drug Administration (FDA):** The Foundation stewards a relationship with the FDA at the highest level and regularly collaborates with the Agency regarding best practices for clinical trials and guidance specific to Alpha-1 therapies.
- **Critical Path Institute (C-Path):** In partnership with C-Path, we are providing the input and data to navigate regulatory pathways for clinical trial design and medical product development
- **National Institutes of Health (NIH):** Recommendations by the NIH inform much of the Foundation’s work, including data collection and research through the Alpha-1 Research Registry.

Our Partners, Memberships and Coalitions



SPOTLIGHT: Looking Ahead

Advocates in Action

We recognize the importance of the patient voice and the collective impact the patient community can have on awareness and advocacy. We, along with our team of policy consultants, meet regularly with the NIH and have ongoing conversations with the FDA to determine how best to work collectively to ensure the Alpha community has access to, and approval for, novel treatments and therapies.

We are working with Congress to find a solution to the patient access problem facing Medicare beneficiaries who are not able to obtain a home infusion due to Medicare law. In March 2022, the John W. Walsh Alpha-1 Home Infusion Act introduced a permanent benefit for Alphas to receive augmentation therapy in the home setting through Medicare Part B. This process is ongoing, and we will continue to work diligently with advocates and legislators to meet the needs of the Alpha-1 community.

Alpha-1 Global

A communications platform for the global Alpha-1 community

Alpha-1 resources and educational materials are available in a variety of languages through the Alpha-1 Global website. Alpha-1 organizations and individuals connect to share ideas, strategies, and tools on three main topics: awareness, detection, and access to care. The website also provides access to information on the latest Alpha-1 developments around the world, as well as educational seminars, and an online discussion forum.

The **Alpha-1 Global website** houses useful tools for Alphas interested in advocacy efforts in their respective countries or regions.

The **Alpha-1 Advocacy Pathway** is an interactive platform that provides tools for becoming a dedicated Alpha-1 advocate on a number of levels.

Alpha-1 Global maintains **an extensive global database** of patient, physician, industry, and researcher contacts that spans six continents and is segmented into unique audiences for various communications campaigns.

SPOTLIGHT: Looking Ahead

2023 International Research Conference and Global Patient Congress

We are working to bring together the global Alpha-1 community to promote engagement and collaboration across the board. The 2023 International Research Conference and Global Patient Congress will take place in Dublin, Ireland. This event will provide educational resources, social interaction and networking, and access to international Alpha-1 experts and leaders.

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.



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