Genetic Alliance

26400 Woodfield Road #189
Damascus MD 20872
202.966.5557
info@geneticalliance.org
www.geneticalliance.org

Amazon Board of Directors
c/o Jeff Bezos, board chair
P.O. Box 81226
Seattle, WA 98108-1226

We, the undersigned health charities, are writing to you about the AmazonSmile program. We all (and apparently hundreds of thousands more charities) received your communication about "winding down" the program. You wrote, "However, after almost a decade, the program has not grown to create the impact that we had originally hoped. With so many eligible organizations—more than 1 million globally—our ability to have an impact was often spread too thin." We do not agree.

Several things are wrong with your closing this program, even though we recognize you are under no obligation to donate to charities.

1. The program has an enormous impact, see our statements below. You do not understand the impact of even a few dollars to our very small nonprofits. The effort needed to enroll our members in comparison to the outcome was more favorable than most other activities.
2. After years of training our members to use AmazonSmile, a month's notice to close the program is unconscionable.
3. People who do not have enough income to contribute felt included in supporting our organizations as they bought necessities like food and diapers. This makes the program inclusive in a way many other donation programs are not.
4. Encouraging us to get our members enrolled and then canceling the program feels duplicitous. We worked to get our members to use Amazon and you will now reap the benefits of all of us working for you, effectively recruiting customers.
5. Having our members respond to our Wishlist is also self-serving and has several problems:
    a. We are not looking for items to buy on Amazon, again see below. We are supporting families, providing scholarships, and purchasing aspects of research.
    b. Putting up a Wishlist drives more traffic and more spending at Amazon, with no benefit to us.
6. Amazon is one of the richest companies in the world. It was built on exploiting the long tail – providing a platform for rare and esoteric items to be bought and sold to anyone in the world. It should benefit a whole sector, the health and patient advocacy

organizations, that serve the long tail – individuals who need personalized medicine and care.

7. Jeff Bezos is among the richest men in the world and needs to know the impact of these donations so that he can continue to support this program.
8. You never measured impact, so how could you make the statement "the program has not grown to create the impact we hoped… spread too thin". How about INCREASING the percentage and yes, having a greater impact?

Consider reversing your decision, increasing the percentage, evaluating impact on the measures we find meaningful, and appreciating all that we, health and disease advocacy organizations, have done for your business. We look forward to hearing from you.

Impact Statements

Stickler Involved People used the Smile $$ for our college scholarship program. So, every year, a HS senior got the benefit of a possible $2000 scholarship.
-Pat Houchin, Co-Founder, Stickler Involved People

We got about $3500. That bought a set of dentures for a kiddo. Talk about impact. Simply life changing.
-Mary Fete, Executive Director, National Foundation for Ectodermal Dysplasias

We were able to send 20 memorial gifts to families who lost a baby to generalized arterial calcification of infancy (GACI) with the money we received from AmazonSmile. These gifts are so meaningful to the bereaved parents who receive them. We are a small nonprofit and we don't have many sources of income, so every source of income is important. We also feel that as well as the donations we are losing, we are losing the opportunity to spread awareness, and to allow people to feel that can contribute regardless of their financial circumstances.
-Liz Molloy, Co-President, GACI Global

Phelan-McDermid Syndrome Foundation was getting @$1000 a quarter. We paid for three families' travel and lodging to a natural history study site. Our families are deeply invested in the program and we are very unhappy to see this go. We don't need an Amazon wishlist. We need the Smile program.
-Ronni Blumenthal, CEO, Phelan-McDermid Syndrome Foundation

Every little bit counts for our organizations.
-Jana Monaco, Advocacy Liaison, Organic Acidemia Association

Every dollar is important to small nonprofits.
-Carol Terry, Co-Founder and Board Secretary, Wilson Disease Association

MLD Foundation has definitely benefited from the AmazonSmile program ... it has had an impact! In addition to several thousand dollars a year in donations, which we did not have to dedicate staff and volunteers to gather, this program allowed anyone, no matter how little or much they spent at Amazon, to know they were supporting MLD families – it created community and connection. All MLD-affected families whose tight budgets did not allow for direct donations could participate because AmazonSmile did not take any more cash from their already tight budgets. AmazonSmile's quarterly donation updates let them know their efforts mattered. Our primary programs are centered around compassion for families, and there is never enough money to do all that we want ... AmazonSmile allowed us to help more families in more significant ways.
-Dean Suhr, President, MLD Foundation

It was a nice passive additional source of revenue we could absolutely use. One of the bigger impacts is that it gave everyone in our community the ability to support us through their purchases no matter their financial situation and provided that sense of pride that they were able to contribute in some way.
I agree with others that so many large companies or even individuals don't have a clue how many small nonprofit organizations are doing their best to serve their mission and communities and how impactful any small amount of additional funding, especially when no internal resources need to be expended, makes a difference.
-Susan Thornton, CEO, Cutaneous Lymphoma Foundation

Our impact -- OAA used these funds to reimburse postage for donated special formulas to families living in other countries. This special formula is not available in countries like Guatemala. This formula is the sole nutrition for many children with our rare metabolic conditions.
-Kathy Stagni, Executive Director, Organic Acidemia Association

PXE International pays for the chemical reagents needed in our Thomas Jefferson University research program to find a pseudoxanthoma elasticum (PXE) treatment. Without these funds, we will have to ask our members, many of whom are legally blind to find a different way to contribute. Many of them are on disability and cannot make ends meet. The Smile program allowed them to contribute, even as they bought essentials for their daily lives.
-Sharon F. Terry, President and CEO, PXE International

The 5p- Society would get several hundred dollars a quarter. It made our members feel like they were contributing with each of their purchases. Many of our families cannot contribute by writing a check but they could through purchases.
-Laura Castillo, Executive Director, 5p- Society

We'd been steadily increasing and had just had a company sign on last month.
-Melissa Chaikof, Co-Founder and Board Chair, Usher 1F Collaborative

We are a small and mighty all-volunteer Working Board (with a 1/4FTE Executive Administrator - that's all we can afford) with an international reach. We work to bring together families, clinicians and researchers to accelerate understanding and effective interventions for individuals affected by a RASopathy. The families we support are medically and financially fragile; the clinicians we connect with have extremely high caseloads and use their personal time to support our mutual work; the researchers we connect with stretch out whatever funds they can garner to bring their findings to peer-review. Every. Little. Bit. Helps. AmazonSmile has been instrumental in providing our constituents a way that is meaningful without breaking their banks, in two ways: being a convenient resource for quotidian shopping, and donating to causes like ours. We are one of many small rare disease organizations who want you to know what an impact Amazon Smile is, and what an impact the LOSS of Amazon Smile will be.
-Lisa Schoyer, President, RASopathies Network

We received about $2400 a year and what Amazon doesn't realize is that small nonprofits find that impactful and it is something anyone can participate in without much effort. Their big initiatives may help a few that already get big funding but leave us small organizations struggling along to fulfill our mission.
-Patricia Wood, President, NBIA Disorders Association

Not only does this program provide a financial benefit, it provides an invaluable way of promoting our organization. Each time an individual makes a contribution, they are reminded of our organization and our efforts to increase hereditary cancer awareness. I also believe it is in Amazon's financial interest to continue this program. Personally, I have made 534 orders on AmazonSmile and have chosen to do so on this site rather than another store or website since I know a small portion will go to support our organization.
-Sharon J Perlman, President & Co-Founder, Colon Cancer Alliance for Research and Education for Lynch Syndrome

As a small nonprofit, surrounded by the 'pink ocean' of breast cancer we tend to be overlooked by the general population (as many of you understand). The Amazon Smile program has given individuals an easy way to support the organization in a 'painless' way when doing their regular shopping. We've used the funds to help cover the costs of providing educational opportunities for our Board members. While it may seem inconsequential to Amazon, the comments I've been reading show they've had a profound impact on those of us in the rare disease space, especially.
-Ginny Mason, Executive Director and patient, Inflammatory Breast Cancer Research Foundation

The donations from AmazonSmile's charitable program go directly towards programs and services. This past year alone, we were able to provide scholarships to a number of families affected by Congenital Adrenal Hyperplasia (CAH) to allow them to attend our patient education conference. Another year, the funds helped a mother travel with her daughter from Pakistan to the US, providing the first opportunity to learn from medical experts and meet other patients and caregivers living with CAH. This was a life-changing opportunity.
- Dina Matos, Executive Director, CARES Foundation

We have been promoting this 4-6 times a year and over the years the amounts have grown. It's such as easy way for people to give and a shame to see it go away.
-Sue Friedman, Executive Director, FORCE: Facing Our Risk of Cancer Empowered

Firstly these companies may be making this decision purely based on cost, but if they take this away, all small nonprofits will die and smaller nonprofits do the tasks the larger ones cannot fulfill - patient registries will have to be closed down if nonprofits cannot afford the costs for the admin they do. Our income is still small but our contributions education wise affect all disorders in the future - that knowledge might now never see the light and the accounting software will have to be funded from somewhere else. This decision affects the other businesses contracted also. Taking it away places a larger burden on those with rare disorders to raise enough funds for research and admin and they simply cannot take care of the costs of running such non-profits themselves. This decision will inevitably cause disease disparity.
-An Van Rooyen, Director, Clubfoot Research Foundation

Removing AmazonSmile from our rare disease community does not solely remove a source of income for PSC Partners. AmazonSmile has also become a community builder: Even those with little income who cannot contribute much financially, have come to feel that they are making their contribution to research through AmazonSmile. AmazonSmile has an impact similar to that of holding a community bake sale, of doing something positive for our rare-disease community. We painstakingly built up AmazonSmile to be a powerful way of helping the community. Removing this important tool feels like Amazon has betrayed us.
-Ricky Safer, CEO, PSC Partners Seeking a Cure

AmazonSmile is a very inclusive fundraising program that allows every individual to act in support of the mission of our organization through their individual purchases at Amazon. While we would welcome a much larger donation from Amazon to our rare disease organization which is working to end preventable brain damage and death in newborn babies, we value each and every person who donates through AmazonSmile and the donation Amazon makes on their behalf. These donations have made it possible for us to distribute posters on the signs and symptoms of hypoglycemia in 23 languages. The posters provide medical professionals with instructions for managing hypoglycemia in newborns to prevent brain damage and death. The AmazonSmile program is essential to us in spreading this important lifesaving message.
-Julie Raskin, Executive Director, Congenital Hyperinsulinism International

Costello Syndrome Family Network is a very small non-profit organization for a rare syndrome. We promote Amazon Prime to our families and friends as a way to raise funds which help pay for the biennial conference that brings families together with experts and researchers. The funds we receive from Amazon DO make an impact! Please include us in your letter.
-Sandra Taylor, Executive Director, Costello Syndrome Family Network

AmazonSmile has been a critical element of our yearly fundraising and necessary to provide programs to our rare disease population. Barth Syndrome Foundation is a small but mighty community, and we rely on funding where we can get it. These funds contribute to the development of potentially life-changing therapies (of which there are presently none!), support advocacy programs, and help families navigate the care of loved ones with Barth syndrome. We have promoted AmazonSmile, especially in our year-end giving, as a great and important way for our constituency to purchase gifts all while doing good for a mission that they are passionate about supporting. We encourage you to please reconsider reinstating this program that has been instrumental, especially for smaller foundations such as ours, to fund critical work that otherwise would not be possible.
- Emily Milligan, Executive Director, Barth Syndrome Foundation

The United Mitochondrial Disease Foundation (UMDF) has been participating with AmazonSmile for years and it was such an easy way for people to contribute. Living with mitochondrial disease is taxing on families and leaves very little time or energy to fundraise or raise awareness. AmazonSmile gave them a simple way to make a difference and gave us anywhere between $5-6K per year. In the nonprofit world, those are always much needed funds! Unless you are living with a rare disease, like the thousands of families within the Genetic Alliance Community, you cannot know the sense of purpose and comfort this gives to families. I personally shop AmazonSmile - and probably way too much - and I do so because I know some of my dollars go to the patients and families we serve.
-Kara Strittmatter, Director, The United Mitochondrial Disease Foundation (UMDF)

Amazon Smile has helped our organization with the funds raised, and engagement from our community has been wonderful. Many have had friends and family also sign up for the program to support our organization, and they have found it to be a great way to have funds come to our org, while shopping. Many use Amazon a lot for basic needs as rare families, and we have promoted the program before major holidays, Prime Days, etc with great use of the program. Many families that cannot afford to donate otherwise, do use Amazon Smile. We also had patients and caregivers directly asking for if we were in the program, so they could support our organization. We are so thankful for it, and sad to see the program ending.
-Karen Durrant, President and Founder, Autoinflammatory Alliance

We are so grateful to Amazon for the Smiles Program. Through these funds, we are able to allocate extra funding to families of children going through a bone marrow transplant.
-Sumathi Iyengar, Co-Founder and Executive Director, Wiskott-Aldrich Foundation

It is an easy way for members of our community to give back without having to write a check. Every dollar counts in rare disease.
-Jill Chertow, President, Propionic Acidemia Foundation

What may seem a small amount to others can help non-profits organizations like ours make a positive impact in the rare disease community. It is also an accessible way for many to be involved in helping to make a difference.
-Katie Sacra, Co-Founder, Bubba's Light

Over the years, the contributions Emily's Entourage has received from Amazon Smile have been significant and supported our efforts to accelerate research and therapeutic development for individuals with cystic fibrosis that do not benefit from existing mutation-targeted therapies. Especially during financially challenging times, the Amazon Smile program has also provided a way for individuals without discretionary income to take an active role in supporting our mission simply through purchasing essential items through Amazon.
-Emily Kramer-Golinkoff, Co-Founder, Emily's Entourage

Every dollar raised for Rett syndrome makes a significant difference. This is one way that our community can give back without taxing them with additional giving. The International Rett Syndrome Foundation is very grateful for the $67,000 that we have received from AmazonSmile since its inception. This is fueling research toward a cure and empowering families affected by Rett syndrome. Please continue the program. Thank you!
-Timothy Frank, Chief Marketing & Development Officer, International Rett Syndrome Foundation

Each year we use the Amazon Smile funds to support our life enrichment scholarships. The scholarships support needs that impact quality of life such as money to pay for fuel and parking for doctors' appointments, eyeglasses, fees for Girl Scout dues, a dance class, etc.
-Cindy Scurlock, President, Turner Syndrome Society of the United States

The funds we've raised thru Smile Amazon have helped to get families to screenings for clinical trials and also other unaffordable medical help for families when needed. It's been a wonderful resource that makes these things possible families who are restricted to one income.
-Patty Taormino, Vice President, Team Sanfilippo Foundation

The AmazonSmile program has significantly impacted our ability to grow and connect the global Usher syndrome community. We've used the funds to continue striving for full accessibility and inclusivity. Our AmazonSmile donations have helped cover the costs of sign language interpreting to provide equal access for deafblind participants at our USH Connections Conferences and volunteers in our international ambassador program. Our small organization's growing AmazonSmile donations in 2022 covered the cost of over 15 hours of captioning for educational videos about emerging research to treat Usher syndrome, a rare syndrome and the leading genetic cause of combined deafness and blindness.
- Krista Vasi, Executive Director, Usher Syndrome Coalition

Our organization received approximately $1,000 per year from the program. This provided funding for one academic scholarship for an individual living with Cystinosis each year.
-Christy Greeley, Executive Director, VP Research, Cystinosis Research Network

The AmazonSmile donations from our community shopping were enough to cover the cost of postage each year for mailing informational packets to newly diagnosed families - a tremendous impact when families need the support and resources the most.
-Glenna Steele, Executive Director, Glut1 Deficiency Foundation

HCU Network America depends on Amazon Smile donations to help fund our patient outreach programs. Since it's community that helps us get these donations, we give it back via scholarships for travel to our conferences. Without the Amazon Smile donations, we will have less opportunity to provide financial support to bring those underserved families together.
-Danae Bartke, Executive Director, HCU Network America

We have been proud supporters of Amazon Smile for many years and were receiving ~$4000 a year. While that may seem small, we were so incredibly grateful for those donations to help support our critical work in GM1 gangliosidosis research. GM1 is a fatal neurological disease that primarily impacts babies and children. We are the only 501(c)(3) nonprofit in the country entirely dedicated to this condition and the support of a large corporation such as Amazon for rare diseases made a tremendous difference to our work. We felt recognized and now our community must rebuild a new following from the ground up. We are deeply disappointed.
-Christine Waggoner, President, Cure GM1 Foundation

Being a grassroots NPO raising funds to find and cure IRF2BPL. IRF2BPL is an ultra-rare fatal neuro-progressive disorder. We rely heavily on community that may not be able to donate directly but be able to help our foundation with their everyday purchases through Amazon! Taking away this lifeline not only for Yellow for Yiannis but the others is completely asinine. Literally, every cent adds up and is going towards lifesaving research!! We ask that you all please reconsider!!
-Angela Papzoglou, CEO, Yellow for Yiannis

We are very grateful to the Amazon Smiles Program for the generous support you give to our organization. We receive over $1,800 annually! This money helps us support a program to have our new families be greeted into the Network by an RN who helps them understand the disease and gives them resources for raising their child. With your help, we are able to send a Welcome Gift to them including a first aid kit filled with items that can help to stop bleeding which is difficult for HPS kids. Another great benefit of the program is that it enables EVERYONE to get involved. Our disease is fatal and has no treatment but this Program provides hope and is, in itself, medicinal allowing everyone to be part of the solution.
-Donna Appell, Executive Director, Hermansky-Pudlak Syndrome Network (HPS)

Pull-thru Network received an average of $400 a quarter. Those funds helped us provide scholarships to 2 youth to attend camp each year. We really have no need for a Wish List, We do need the funds created through AmazonSmile. We are very disappointed to see this end.
-Lori Parker, Executive Director, Pull-thru Network

Amazon Smile is one of the easiest and most effective ways for our supporters to provide ongoing contributions to our organization, which contributes to our foundation's sustainability. The amounts raised may not seem meaningful to a multi-billion dollar company like Amazon, but they certainly are meaningful to small grass-roots charities like us. Please reconsider discontinuing the program, and allow your customers to continue to feel good about shopping with you while supporting their favorite charity and benefitting the 1 million+ nonprofits registered with AmazonSmile.
-Michaelle Jinnette, President, Cure KCNH1 Foundation

The funds we received from the AmazonSmile program last year helped us cover travel expenses for three families to attend our Community Connections Family Conference - this was a life-changing event for our rare disease families, many of whom had never met another family whose child suffers from the same disease.
-Lisa Manaster, President, CACNA1A Foundation, Inc.

Amazon Smile has been a great way for our community to help support the mission and programs of the GFPD. It has been an accessible fundraiser for thousands of members of our community to allow them to feel like they are making a tiny difference through their amazon purchases. We are disappointed to see this program end and hope to have other ways to collaborate with amazon in the future.
-Melissa Bryce, Executive Director and Co-Founder, The Global Foundation for Peroxisomal Disorder

Connie Lee, Founder and CEO, Alliance to Cure
Robert Marshall, Executive Director, Alstrom Syndrome International
Robin Dubin, Executive Director, AliveAndKickn

Sincerely,

Sharon F. Terry
President and CEO, Genetic Alliance
sterry@geneticalliance.org