

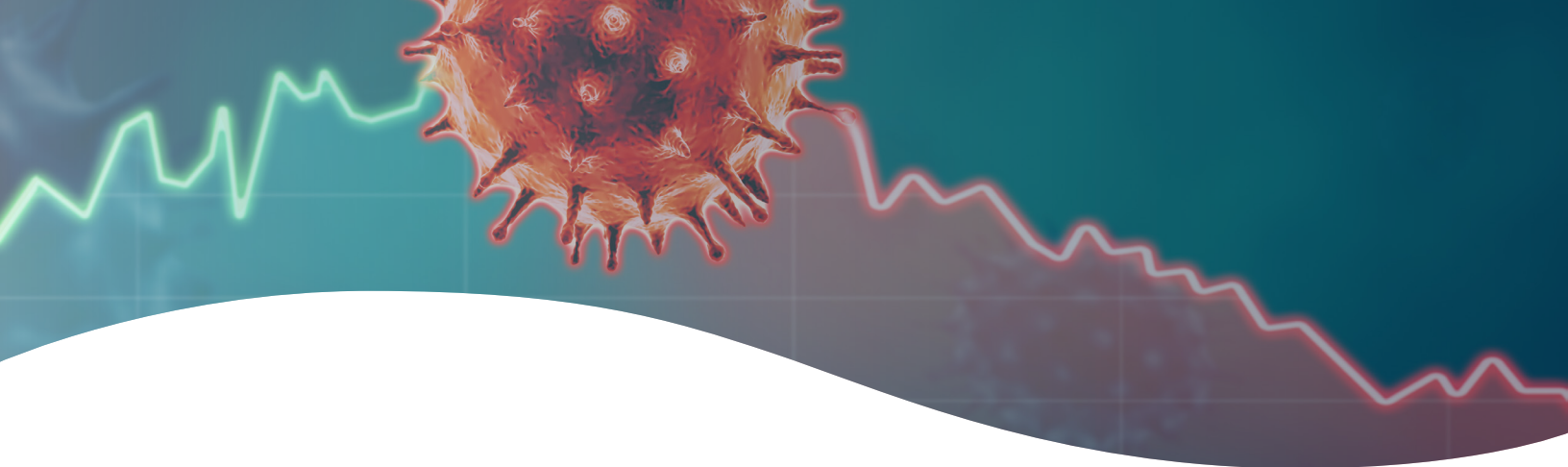


Continuity of Care Rare Patient Impact **GRANT PROGRAM REPORT**

February 2021

COVID-19





The COVID-19 pandemic continues to take a toll on human life. As vaccines that promise to arrest the pandemic are being distributed, measures of the pandemic's devastation continue to climb with the numbing regularity of an odometer on a car barreling down the highway. At the end of 2020, more than 83 million cases of the virus had been detected and more than 1.8 million people had died from the disease. In the United States, nearly 350,000 people had died.

While the growth of technology companies and an aggressive intervention from the Federal Reserve Bank have kept the stock market at near record levels, impacts of the pandemic have disrupted the global economy through measures ranging from GDP to new claims for unemployment. The macroeconomic figures and indicators can potentially dilute the acute, intense pain and fear of people struggling to meet their daily living expenses, pay the rent, and put food on the table.

For people with rare diseases and their families, the pandemic has delivered an additional wallop. Rare disease patients, many of whom face a heightened risk from infections, have found themselves isolated, have had access to treatment disrupted, and have struggled to meet the financial burdens that come with living with a rare disease. In May 2020, a National Organization for Rare Disorders survey about the effects of COVID-19 on



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the rare disease community found that 40 percent of the households had suffered a loss of income. What's more, 29 percent of the respondents reported that they had temporarily or permanently lost jobs due to COVID and that 11 percent of the job loss resulted in the loss of health insurance.

While 69 percent of the survey respondents reported problems with access to medications, 10 percent of those people said it was because they could no longer afford them because of lost income.¹

In response to the COVID-19 pandemic, Global Genes expanded its RARE Patient Impact Grant program to assist members of the rare disease community who were struggling due to the global pandemic. Alexion Charitable Foundation, Alnylam Pharmaceuticals, Genentech, and Horizon Therapeutics made the expansion of the program possible through their financial support.

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¹COVID-19 Community Survey Report, National Organization for Rare Disorders, May 5, 2020, https://rarediseases.org/wp-content/uploads/2020/05/NRD-2061-RareInsights-CV19-Report_v2-2.pdf, accessed 1/15/20

In April 2020, the organization introduced the Continuity of Care RARE Patient Impact Grant to address needs of the rare disease patient community created by the pandemic. Global Genes provided the grants to members of its RARE Foundation Alliance, as well as rare disease patients, caregivers, and support groups not affiliated with a Foundation Alliance member. Global Genes provided the grants to address pandemic-related needs in four areas.

Through the program Global Genes awarded more than a total of **\$500,000** in grants that **provided support to over 4,500 patients and households.**



These included grants to connect rare disease patients to a network of telehealth and psychosocial counseling services, grants to support special education and distance learning teachers, grants to provide support for basic medical needs and resources, homeschooling tools and resources, and grants to access career counseling services.

“The COVID-19 pandemic represented an unprecedented public health threat that required dramatic steps be taken to minimize the risk of spreading the disease, but these efforts caused gaps in access to essential services and economic dislocation that caused some rare disease patients and caregivers to suffer unintended consequences,” said Craig

Martin, CEO, Global Genes. “It was imperative that we expand our RARE Patient Impact Grant Program to help our community under these extraordinary circumstances.”

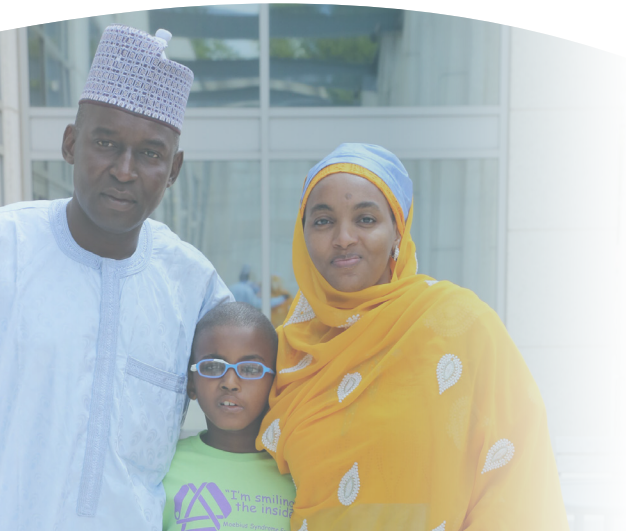
Supporting the Rare Disease Community

Through the program Global Genes awarded more than a total of \$500,000 in grants that provided support to over 4,500 patients and households. Global Genes awarded grants on a rolling basis. Member foundations and support groups were eligible to receive up to \$20,000 each while individual rare disease patients and caregivers could receive up to \$2,500 each.

The overwhelming portion of the funds—some 82 percent—provided assistance with basic living expenses, caregiver expenses, medical transportation, and personal protective equipment. Education (11 percent), telehealth (5 percent), social support (1 percent) and career counseling (1 percent) accounted for the balance of the funds.

The Global Genes RARE Foundation Alliance is a coalition of more than 750 rare disease organizations. These organizations work with Global Genes to have a collective impact, to network, and to improve their capacity through access to tools, training, and resources. Global Genes awarded grants to 34 Foundation alliance members. The average size of these awards was nearly \$14,000. These organizations distributed a total of \$474,000. Separately, Global Genes issued an addition 19 awards to individual patients and households at an average award amount of more than \$1,400.

Category Need Indicated



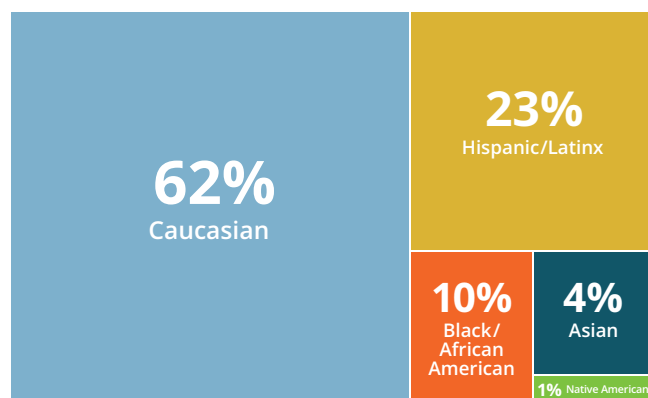
“As the pandemic hit, our families like many other in the rare disease community, were challenged like never before.”

—The Alagille Syndrome Alliance

The grants reached over 4,500 patients and families with an average of four people per household. The average household income of recipients totaled just less than \$36,000. The average age of the rare disease patients in households that received grants was a little more than 9 years old. Some 82 percent of recipients lived in the United States with grants made to patients in 45 states and Puerto Rico. The grants also went to families in Columbia, Peru, Canada, India, United Kingdom, Australia, South Africa, Saudi Arabia, Russia, Belgium, Iceland, Ireland, Singapore, and Romania.

A total of 62 percent of recipients identified themselves as Caucasian. Hispanic/Latino recipients accounted for 23 percent of the grants, followed by Black/African American (10 percent), Asian (4 percent), and Native American (1 percent).

Race/Ethnicity



Making Ends Meet

For many members of the rare disease community, the financial challenges of daily living intensified through sudden job loss or cutbacks in work hours. “As the pandemic hit, our families like many others in the rare disease community, were challenged like never before,” the Alagille Syndrome Alliance told Global Genes. The organization noted that parents and caregivers had already become accustomed to losing work hours to care for a sick child or themselves, had been accustomed to distancing their child



or themselves from others who were sick, and had grown used to the stress on themselves and their families. But nothing prepared them for this.

“They had made lost hours at their job work for their family any way they could, but they were not prepared for more hours being cut and even losing their jobs,” the organization said. “The kind of distancing to keep themselves or their child safe was nothing compared to the loneliness and isolation this pandemic has caused. And the stress already being handled has now become more than some can bear.”

The grant provided to the Alagille Syndrome Alliance allowed it to help ease some of the financial burden of its families. The funding was used for a range of purposes, but in a number of instances covered mortgage and rent payments for rare disease families. “The Global Genes Continuity of Care RARE Patient Impact Grant has allowed us, as an organization, to alleviate some of the burden on our families,” the organization said. “The funding has allowed us to help bridge the gap with the lost wages and the ability to just pay rent to avoid eviction. It has allowed us to alleviate some stress and make a greater impact on an already suffering community.”

The GRIN2B Foundation, through the Rare Impact Patient Grants, assisted people who suffered a loss of wages meet their basic living expenses, funded needed home repairs, purchase specialized medical equipment, and covered the cost of transportation to medical appointments. In all, the organization distributed more than \$15,000 in grants.

“In normal times, our families struggle to meet the demands of their child with GRIN2B in addition to their other children, work, and home,” said Liz Marfia-Ash, president of the GRIN2B Foundation, which made grants to 17 families. “Everyone is hanging on by a thread with schools being closed and losing access to therapies. With no end to this pandemic in sight, many families are losing hope.”

“Global Genes’ support has made a substantial difference in the daily lives of our community members, many of whom are now able to access distance learning, attend telehealth appointments, visit their hematologists, and maintain a residence with water and power.”

—The Hemophilia Foundation

A Digital Connection

The Continuity of Care RARE Patient Impact Grants have also played a critical role for families to remain connected to schools and healthcare providers through technology. The Angelman Syndrome Foundation issued more than \$20,000 in a total of 23 grants for rare disease patients to purchase iPads for virtual learning or to cover the cost of telehealth services through an Angelman Syndrome Foundation clinic.

In one instance, the organization said a parent with three children had no way for all of her children to participate in virtual learning because they had no computer or tablets. Now, each one of them is equipped with their own device and can connect with their teachers, therapists, and friends.

For others, the grant allowed children to continue needed occupational, speech and feeding therapy from home. Some parents feared that in the face of the stay-at-home restrictions and the disruption to therapy and their daily routines, children would act out, and grow frustrated by difficulties communicating. “This would lessen her outbursts and self-injurious behaviors,” said one parent. “She will get her needs met and improve her self-esteem

to know that her thoughts, feelings, and emotions were understood and being heard.”

The Hemophilia Foundation of Southern California issued nearly \$20,000 in grants through a total of 54 gifts ranging from \$125 to \$500. While many of these grants addressed helping families pay bills, several provided internet connectivity or technology that allowed students ranging from kids to a college to attend classes online and study. Others, who were unable to see their hematologist, were able to engage in telehealth appointments because of the grants.

The Angelman Syndrome Foundation issued more than **\$20,000** in a total of **23 grants.**

The Hemophilia Foundation of Southern California issued more than **\$20,000** in a total of **54 grants.**

“Global Genes’ support has made a substantial difference in the daily lives of our community members, many of whom are now able to access distance learning, attend telehealth appointments, visit their hematologists, and maintain a residence with water and power,” the Hemophilia Foundation of Southern California said. “Inquiries for financial assistance have grown substantially, as members suffer job loss and endure reduced work hours, in addition to coping with their loved one’s health condition.”





“The needs persist and the employment loss due to the pandemic will continue, so our community is still in desperate need, but the funds from this grant made a significant impact during the past six months.”

—Life and Family Foundation of Virginia

Bare Necessities

The loss of work due to the pandemic created dire circumstances for many. While many grants were used to pay for rent or utilities for families that had fallen behind, in some cases organizations were able to assure that families didn't go hungry.

“We furnished food to another family as they were without food and did not have any immediate resources for a resolution,” Life and Family Foundation of Virginia said. It noted it was able to provide career counseling to another parent, who was able to obtain additional income for sustainable financial independence.



Even a few days without sufficient **medical nutrition** can damage a patient.

In other instances, because of a patient's specific illness, it is critical to obtain medical foods, which can be costly. That's the case for people with phenylketonuria (PKU), an inborn error of metabolism that prevents people with the condition from being able to metabolize the amino acid phenylalanine. As metabolic waste accumulates, the condition can lead to intellectual disability, seizures, behavioral problems, and mental disorders.

National PKU News was able to leverage the grants to raise additional contributions. It said it heard from dozens of families that the grant provided one to two extra months of medical food that they otherwise would not have been able to afford.

“This directly translates into improved health of the individuals in these families with inborn errors of metabolism, because even a few days without sufficient medical nutrition can damage a patient,” the organization said. “The needs persist and the employment loss due to the pandemic will continue, so our community is still in desperate need, but the funds from this grant made a significant impact during the past six months.”

Finding Work

Many of the grant recipients were just scrapping by prior to the pandemic, but lost hours and jobs because of the economic dislocation that resulted. The demands of parenting for a child with a rare disease and balancing that with work are challenging during normal times. As children sheltered in place, parents often had to stay at home to care for children.

One family with three children under the age of ten, all of whom are non-verbal and not mobile, suffer frequent seizures and need constant supervision. The father works part time and during the pandemic the mother has been unable to work outside the home. In another instance, a woman who is the sole provider for her family, because her husband cares for their son with a rare neurodevelopmental disorder, was laid off. She has found some alternative work from home working in telehealth. “We already had such a tight budget before COVID-19,” she said, “and now it's even tighter.”

Though a small portion of the grants have been used for career counseling services, in some cases they have had big impacts. One woman who lives alone with an annual income of about \$9,000 a year was able to get career counseling thanks to a grant through the Life Family Foundation of Virginia. That has allowed her to nearly double her annual income, increasing earnings by about \$8,000 a year.



Small Grants, Big Impacts

Grant recipients faced many challenges prior to the outbreak of COVID-19, but the pandemic intensified these by deepening the isolation rare disease patients and their families experience. Already under the strain of the medical and related costs of living with a rare disease, the small grants made big impacts on recipients by addressing an immediate need, defusing a crisis, or equipping them with essential technology to get through the pandemic. At a time when members of the rare disease community may have felt more alone than ever before, it let them know there were people there to help them.

Beyond the direct impact on the people who received funding through the Continuity of Care Rare Patient Impact Grant Program, organizations noted some unintended benefits. It increased the global reach of organizations. As patients

gained access to technology to connect with their doctors, they were able to use it for viewing events, online learning, and connecting with others. And organizations were able to leverage the grants to secure additional support from other funders because it helped them establish credibility.

While vaccines have offered hope of the pandemic coming to an end, the reality is that for many rare disease patients and their families, the difficult circumstances created by the outbreak have changed little. Global Genes is continuing the program as long as funds allow. It is also collaborating with a number of its partners to address unmet needs within the rare disease community and address questions about recovery, vaccination, and research. ■

About Global Genes®

[Global Genes](#) is a 501(c)(3) nonprofit organization dedicated to eliminating the burdens and challenges of rare diseases for patients and families globally. In pursuit of our mission, we connect, empower, and inspire the rare disease community to stand up, stand out, and become more effective on their own behalf—helping to spur innovation, meet essential needs, build capacity and knowledge, and drive progress within and across rare diseases. We serve the more than 400 million people around the globe and nearly one in 10 Americans affected by rare diseases. If you or someone you love has a rare disease or are searching for a diagnosis, contact [Global Genes](#) at 949-248-RARE or visit our [resource hub](#).

Please consider supporting the rare disease community through our RARE Patient Impact Program by texting **RARE** to 41444 or by visiting www.globalgenes.org/donate-now



28 Argonaut, Ste. 150
Aliso Viejo, CA 92656
+1-949-248-RARE (7273)

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