

Atlantis Health Report Reveals New Ways to Increase Rare Disease Patient Support Program Enrollments

Global research study investigates patient and caregiver awareness of and enrollment in rare disease support programs, services and organizations

SUMMIT, NJ, UNITED STATES, September 13, 2023 / EINPresswire.com/ -- Atlantis Health, a leading global patient agency specializing in the latest behavioral science, today announced it has officially released the Atlantis Health [Rare Disease](#) Support Report, which found that people living with rare diseases and their caregivers have low awareness of and enrollment in pharma-sponsored support programs.

As a result, they may be missing out on both emotional and practical support such as medication reminders that they could be getting. However, the report also reveals that caregivers and nurses are likely the key to improving rare disease patient support program enrollment levels.

Low Awareness of Pharma-Sponsored [Patient Support Programs](#) vs. Support Organizations
The report found that only 33% of people living with rare diseases and 31% of their caregivers on average worldwide were aware of pharma-sponsored patient support programs and services. This was significantly lower than their awareness of relevant rare disease support organizations, which was 67% for patients and caregivers on average. The difference in awareness levels indicates the need for pharmaceutical companies and rare disease startups to better promote their rare disease patient support programs, especially in Germany and the UK where average patient awareness levels were only 0% and 12% respectively.

Higher Enrollment in [Pharma Patient Support Programs](#) by Caregivers vs. Patients

A new and important finding of the Atlantis Health global rare disease support research study was that 71% of caregivers who were aware of pharma-sponsored support programs or services enrolled in them compared to only 54% of people living with rare diseases. So, increasing awareness with rare disease caregivers may hold the key to increasing enrollments in pharma-



Rare Disease Support Report Q3 2023

Part 4 of the Evidence for Change Research Series



Atlantis Health Rare Disease Support Report Reveals Key to PSP Enrollments



Rare diseases require ongoing support. Our new global study shows that caregivers and nurses are key to improving rare disease awareness and enrollments in pharma patient support programs.”

Jonny Duder, CEO of Atlantis Health

sponsored rare disease patient support programs.

However, the report found that rare disease caregivers in the US were 52% less likely to be aware of pharma-sponsored patient support programs than people living with the rare diseases themselves. This was also true in Australia where rare disease caregivers were one-third less likely to be aware of pharma-sponsored patient support programs. These findings indicate a clear opportunity for pharmaceutical companies and rare disease startups to more actively promote their rare disease patient support programs to caregivers, especially in the US and Australia.

Tapping into Nurses vs. Primary Healthcare Providers for Practical and Emotional Support

The report also found that 44% of people living with rare diseases and 20% of caregivers in the US, UK and Germany received additional support services from a nurse separate from their primary healthcare provider. So, it is important that pharmaceutical companies and rare disease startups include nurse delivered support through the digital patient support programs they offer to provide a more complete solution to people living with rare diseases and their caregivers.

Rare Disease Support Implications

The main implications of this report are that living with a rare disease can place significant demands on both patients and their caregivers. Our research demonstrates that both are seeking additional support to help manage these demands – whether medical, practical, and/or emotional.

The promising aspect of this report is that people living with rare diseases and their caregivers can get more support than many of them do today if they enroll in pharma-sponsored patient support programs and get support from nurses as well as their primary healthcare providers. So, the key takeaway is that pharmaceutical companies can help facilitate better rare disease support by more actively promoting their PSPs to caregivers, who are more likely to enroll, and by enabling nurses to provide support through their digital patient engagement programs.

“Rare diseases are serious, often chronic and progressive diseases that require ongoing support for both people living with the disease and their caregivers,” said Jonny Duder, CEO of Atlantis Health. “Our new global research study shows that they may be missing out on support they could be getting because of low awareness and enrollments in pharma-sponsored rare disease support programs unless caregivers and nurses are brought into the solution.”

About the Atlantis Health Rare Disease Support Report:

- Purpose of the global research report: determine the support needed for people living with rare diseases and their caregivers
- Global study with participants from USA, UK, Germany, and Australia
- Surveyed 72 people living with rare diseases and 45 caregivers
- A wide range of rare diseases were represented including genetic and non-genetic conditions, cancers, and autoimmune conditions
- Study completed and released Q3 2023
- To access the report, go to https://atlantishealth.com/rare_disease_support_campaign/

About Atlantis Health

As a global patient agency and strategic partner to pharmaceutical and life sciences companies, Atlantis Health co-designs and delivers personalized patient engagement solutions using the latest behavioral science.

Atlantis Health helps clients achieve better outcomes with behavioral science including:

20% average increase in treatment adherence

80%+ patient retention over time

80%+ average satisfaction

For 25 years, we've helped pharmaceutical and life science companies dramatically improve new product launches, medication adherence and health outcomes by designing and delivering personalized patient engagement solutions with our leading behavior change strategies, techniques and technology.

Additional Resources

- Follow Atlantis Health on LinkedIn: <https://www.linkedin.com/company/atlantis-health/>
- Schedule a free 30-minute consultation at https://atlantishealth.com/rare_disease_support_free_consultation to learn how we can help you co-design or optimize a rare disease patient engagement program utilizing our configurable digital platform that incorporates both caregivers and nurses

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