

# Atlantis Health Rare Disease Report Reveals Real Reasons for Rare Disease Medication Nonadherence

*Global rare disease study finds that main reason for nonadherence is NOT forgetting but is intentional and related to feelings about their disease and treatment*

SUMMIT, NJ, USA, July 12, 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 Nonadherence Report](#), which provides insights into the real reasons why people living with rare diseases stop taking their medication.

To uncover new insights the study utilized the Intentional Non-Adherence Scale (INAS) – a new validated tool which specifically looks at the issue of intentional nonadherence. Questions asked in this scale are seldom used in either the clinical setting or in support services.

Surprisingly, the report found that the main reasons for treatment nonadherence among people with rare diseases are related to people's thoughts and feelings about their disease and treatment.

Until now, it was believed that the main reason people living with chronic and rare diseases stopped taking their medication was because of forgetting. But it turns out that for most people it's a conscious choice – they don't want to take their medication because they are resisting the illness.

Top 3 Reasons for [Rare Disease Nonadherence](#):

- 1) 55% - Because I want to lead a normal life again
- 2) 51% - Because it is inconvenient to take all the time
- 3) 49% - Because I want to think of myself as a healthy person





Rare diseases are serious, often chronic and progressive diseases that rely on patients and their families accepting and adhering to treatments long term to improve health outcomes.”

*Jonny Duder, CEO of Atlantis Health*

“Wanting to lead a normal life”, “not wanting to take medicine all the time” and “wanting to think of themselves as healthy” are all indications that people living with rare diseases have not fully accepted their disease and treatment plan.

Instead, these findings indicate that people are still psychologically resisting their illness. As a result, they intentionally sabotage their own treatment by resisting and/or stop taking the medication they are prescribed.

The report also found that “resisting illness nonadherence” increases over time. And, that people living with rare

diseases for 6-12 months are the most likely to stop following the doctor’s prescribed treatment plan and start testing treatment to see if they feel okay without it.

### Rare Disease Nonadherence Implications

The main implications of this report are that people living with rare diseases and their carers need highly personalized psychosocial support to help accept their illness and prescribed treatment plan. And, this education and support isn’t just needed when they are diagnosed. They need continuing education and support over time, especially as they may start to feel frustrated and fatigued by the impact of living with a rare disease. Rather than resisting their illness at this point, patients can be supported to find acceptance and commit to value-based action so they can continue to live the life they want – and continue to take treatment as prescribed.

The promising aspect of this report is that the nonadherence risk factors can be uncovered through assessment both in person and remotely and are modifiable with the correct support interventions.

### Rare Disease Nonadherence is a Major Global Problem

Atlantis Health conducted this new, original global research study and published this report as part of its Evidence for Change behavioral science research series.

The focus of this particular report was rare disease nonadherence because this is a major emerging global health issue that requires more study.

Although only 5% of the global population have been diagnosed with a rare disease, rare diseases routinely account for 13% of deaths annually, according to the National Institute of Health.

And, rare disease [medication nonadherence](#) rates are 58-65%, which are among the highest of any diseases.

“Rare diseases are serious, often chronic and progressive diseases that often have a significant impact on mortality and QOL,” said Jonny Duder, CEO of Atlantis Health. “New rare disease treatments are making a significant impact on these outcomes however it relies on patients and their families accepting and adhering to treatments long term. It’s therefore critical that we get these rare disease nonadherence findings out - especially to rare disease medication and care providers worldwide - because together we can design and deliver solutions that help people living with rare diseases accept their disease and treatment plan to ensure patients receive full the benefit of treatment to improve long term outcomes.”

About the Atlantis Health Rare Disease Nonadherence Report:

- Purpose of the global research report: determine the main reasons for nonadherence among people living with rare diseases
- Global study with participants from USA, UK, Germany, Australia, and New Zealand
- Surveyed 72 people living with rare diseases
- Administered 13-question survey using the Intentional Nonadherence Scale (INAS)
- Participants have lived with their rare disease for varied lengths of time
- Participants have various types of rare diseases
- Over half of the participants take 3+ medications
- Nearly two-thirds of the participants take tablets/capsules
- Nearly three-quarters of the participants take medications once or more daily
- Study completed and released Q2 2023
- To access the report, go to

[https://atlantishealth.com/us/rare\\_disease\\_nonadherence\\_campaign/](https://atlantishealth.com/us/rare_disease_nonadherence_campaign/)

About Atlantis Health

As a global patient agency and strategic partner to pharmaceutical and life sciences companies, Atlantis Health co-designs and delivers 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 Atlantis Health by sending us a contact us form and indicating your location at <https://atlantishealth.com/contact/>

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