



SMART Approach

From Dismissed Pain to Precision Empowerment: A Young Woman's Journey with Hereditary Chronic Pancreatitis

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1. Introduction

The patient's voice is a vital pillar of precision medicine⁽¹⁾, particularly when addressing the complex challenge of severe or chronic visceral pain. In this article, a young woman shares her personal journey with hereditary chronic pancreatitis. From years of misdiagnosis and dismissed pain attributed to constipation and acid reflux, through genetic confirmation at age 15, to developing practical self-management strategies, she illustrates how precision diagnostics combined with patient-centered care can transform outcomes. Now serving as a patient advocate at the National Pancreas Foundation, she highlights three actionable strategies—consistent electrolyte hydration, effective physician communication, and refusing to let pain define one's identity—and calls on clinicians to integrate cutting-edge genetic insights with compassionate listening and behavioral support to better empower patients living with chronic pancreatitis pain

2. Patient Perspective

For many years, I questioned why my pain continued without a clear solution. Doctors repeatedly attributed my symptoms to chronic constipation and acid reflux, yet these explanations never fully accounted for the severity I experienced. The pain disrupted my daily life from early childhood until age fifteen, when I was finally diagnosed with hereditary chronic pancreatitis caused by mutations in the *PRSS1* and *CFTR* genes. The diagnosis came after an episode of excruciating pain left me struggling to breathe. In that moment, I received something I had longed for—validation that my pain was real.

Genetic testing provided the precision diagnosis that changed everything. I immediately began pancreatic enzyme replacement therapy (PERT) and adopted a low-fat diet. These interventions relieved some of the pain, but adapting my entire life around chronic pancreatitis

proved unsustainable for an active teenage girl. The experience ignited my passion for advocacy and exposed a critical gap in the medical community: the frequent under-recognition of chronic visceral pain in genetically driven diseases.

Over time, I developed a more balanced approach that integrates dietary mindfulness, physical activity, and self-advocacy. Through this process, I discovered three practical strategies that have transformed how I manage my pain: consistent hydration with electrolytes, open communication with my care team, and refusing to let the disease define my identity. These strategies not only help me cope but also empower me to advocate for others living with chronic illness pain.

3. Maintaining Hydration

Staying hydrated is one of the simplest yet most effective tools for preventing flare-ups. While most physicians recommend hydration for general health, I learned that consistent intake of electrolyte-enhanced fluids specifically reduces fatigue, improves appetite, and decreases pain episodes. Consistency is key—it requires daily discipline, but even small improvements (more than one glass of water a day) make a measurable difference. There is no such thing as “perfect” hydration when managing genetic pancreatitis, but the effort itself prevents many painful setbacks.

4. Communicating Effectively with Physicians

After diagnosis, I still endured severe pain despite appropriate treatment. I eventually told my physicians I was mentally burned out from taking multiple Creon pills daily with little relief. That honest conversation led to a higher PERT dose and a referral to a behavioral therapist for additional coping tools. Physicians cannot feel our pain, no matter how advanced the imaging or labs. Learning to describe

Abbreviations used in this paper: CFTR, cystic fibrosis transmembrane conductance regulator (the cystic fibrosis gene); PERT, pancreatic enzyme replacement therapy; PRSS1, Protease, Serine 1 (the trypsinogen gene)

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my symptoms clearly and collaboratively has been instrumental in refining my personalized care plan and improving my quality of life.

5. Refusing to Let Pain Define Me

Resisting the tendency to let chronic pancreatitis pain dictate who I am has been an ongoing journey. The symptoms shape my daily schedule, but they do not define me physically or mentally. This is not denial—it is reclaiming agency. I stay physically active, maintain normalcy where possible, speak openly about my experience, and challenge

the narrative that genetic pancreatitis limits my opportunities. I am more than my disease; I am a young woman actively battling it and pushing my limits every day.

My journey from years of dismissed childhood pain to a genetically confirmed diagnosis of hereditary chronic pancreatitis (*PRSS1* and *CFTR* mutations) underscores a powerful truth in precision medicine: knowing the genetic cause is only the beginning. Targeted therapies like optimized pancreatic enzyme replacement and personalized lifestyle strategies can reduce suffering, but true healing.

References

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