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An open letter to the primary ovarian insufficiency community

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TO THE EDITOR

I (CMJ) participated in an extraordinary clinical research program, and ask you to join in helping make the contours of that experience available to women and girls living with primary ovarian insufficiency (POI). Too many of us with the symptoms of “early menopause” feel despair and disconnection from having a disease that our healthcare providers often cannot diagnose or treat, and I believe there is a path to alleviate that suffering for women and girls in our communities.

Five years ago, my endocrinologist phoned me at my office to share the results of recent blood work: I had early menopause, or at least the FSH levels of a woman in menopause. While she had performed numerous tests, she could offer no answers for what was causing my missed periods, sleep loss, or sweats on the nights when sleep eventually came. I hung up the phone and found a quiet place so my sobbing would not distract my colleagues. I was 35 and desperately wanted to have children.

A couple of years and many tests later, I participated in a research protocol on POI at the Intramural Research Program of the National Institutes of Health (NIH) in Bethesda, Maryland. When first admitted to the NIH Clinical Center, I still had no diagnosis. But as soon as I met my roommate, I knew something would shift: she experienced the same symptoms and had been diagnosed with POI when she was just 19. Over the next three days, she and I shared our deepest hopes, including those around becoming mothers.

While at the NIH, I met with at least ten medical professionals, including an endocrinologist, nutritionist, psychiatrist, occupational therapist, recreational therapist, spiritual counselor, and the Principal Investigator (LMN) – a reproductive endocrinologist by training. Not to mention the phlebotomists and sonographers! Each explored a different aspect of my well-being. At one point during my stay, the team provided the diagnosis of POI, and like so many others diagnosed after years of uncertainty, I felt tremendous relief at having a name to the condition and the awareness that I was not alone in experiencing it. A consultation with a psychiatrist was equally as powerful: he lifted a heavy burden when he stated that I did not cause my POI. Before leaving, the team at the NIH wove these perspectives together to form the picture of how I had been affected by the condition and a rough roadmap for my future care.

I feel blessed and humbled by my experience at the NIH. Living in Washington, DC, I had convenient access to the NIH, a gynecologist who knew enough to suggest the protocol, and rounds of tests that armed me with the important information on conditions I did not have. Once diagnosed, I had access to on-line resources and a large network of medical professionals, empowered to choose among them until landing on the right network of practitioners.

POI strikes 1 percent of all women and girls by age 40. Many of these women report similar challenges: sporadic menopausal symptoms, lengthy waits to getting diagnosed, emotional trauma, and disjointed healthcare in which advisors have no or very limited knowledge of the disease.¹ The further away from an urban center a woman lives, the more likely she is to go without the care, information, or the types of advocates found at the NIH.

This must change. A clear initial step is to inform more medical professionals about this rare disease, but as with any rare condition, this will never be sufficient. What is needed is a durable approach that at its core empowers women with the knowledge and tailored guidance necessary to make informed choices throughout their journey with POI. To do this effectively, any approach must:

1. be available and accessible to women regardless of geography or socioeconomic status;
2. bring together diverse perspectives, similar to the NIH protocol, including a wide array of medical fields, therapists and spiritual care counselors, in an integrated fashion; and
3. be developed with the individual patient foremost in mind, and tend to her at each life stage.

My time at the NIH was among the most affirming, productive, and caring experiences of my life. Please help me make this possible for others.

I (CME) am also a woman living with POI. I serve as the Executive Director of Rachel's Well, a non-profit organization working to improve women's health. The above story confirms the need to empower women with POI. Our vision is simple: a world in which every woman and girl with POI receives integrated personal care for the condition. Rachel's

Well seeks to build a POI research and patient care community that connects expert knowledge on the management of POI in real time with point-of-service care. We must also identify additional causes of POI and work toward finding a cure.

I (LP) am an Endocrinologist, head of a Research and Clinical Unit in Milan, Italy. I have a special interest in Reproductive Endocrinology and am caring for several women with POI who report stories similar to those above. For these women, we also have a dedicated multi-disciplinary program that includes endocrinologists, gynecologists, psychologists, and nutritionists. In addition, since POI has a familial component, we are conducting research into factors that could be incorporated into a genetic test for the prediction of POI risk. Hopefully, in the near future, this information will allow women at risk to preserve their fertility.

I (PYB) am a molecular geneticist who has dedicated my career to elucidating basic mechanisms of early mammalian development. I am also a Founder and the CEO of Celmatix, a company focused on helping women maximize their fertility. Many researchers, including those at Celmatix, are working diligently to decode what a woman's DNA says about her fertility potential. This personalized information, paired with the right data analytics and digital clinical decision support platforms, holds the potential to revolutionize women's healthcare in our lifetime. Real change for women with POI will be rooted at the intersection between patients, their clinicians, industry, non-profits, and government.

I (LMN) am encouraged. Two women with POI envision a world where all women and girls with the condition receive integrated personal care. They are building a community. A quote from Mother Teresa comes to mind. "I alone cannot change the world, but I can cast a stone across the waters to create many ripples."² Strategic planning is overdue.³ We need a new paradigm for studying and treating POI.⁴ A system that both conducts research and provides integrated personal health care would be ideal, not only for patients with POI but also those investigating the condition (Falorni A, Minarelli V, Eads CM, Joachim CM, Persani L, Rossetti R *et al.* A clinical research integration special program (CRISP) for young women with primary ovarian insufficiency. *Panminerva Medica* [submitted]).⁵⁻⁹

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