Improving the Evidence: Can a Prematurity Registry Change the Game?

Deb Discenza, MA, and Andrea Schwartz Goodman, MSW, MPH

Deb Discenza, MA is the Founder/CEO/Publisher of PreemieWorld, LLC and the founder and community leader of the Inspire Preemie Community at http://preemie.inspire.com. Deb is the co-author of The Preemie Parent's Survival Guide to the NICU and the publisher of two newsletters, Preemie Family and Preemie Pro. She is a founding member of the Preemie Parent Alliance and the original National Coalition for Infant Health. Deb can be reached at deb@preemieworld.com.

Andrea Schwartz Goodman, MSW, MPH, a leader in scaling maternal and child health programs, is most passionate about finding solutions that meet families where they are. She serves on the Steering Committee of the National Coalition for Infant Health, as Senior Editorial Project Director for Neonatology Today, and as Director of Engagement at Genetic Alliance, an organization with 32 plus years of experience serving the disease advocacy community through a people-centered lens. Genetic Alliance created the Platform for Engaging Everyone Responsibly (PEER), a unique, award-winning technology solution for collecting health data directly from individuals. The platform, which has been designed to accommodate a variety of attitudes about data sharing and privacy, meets individuals where they are by giving them complete control over how their data is shared for research

Research has always been a slow path toward the pursuit of peer-reviewed publication and the hopeful implementation into medical practice. With expanding technology and opportunities for global collaboration, the research enterprise finally has its chance to speed up and spread evidence near and far. Disease-focused communities have become robust, intimate, and activated—ready to share ideas, knowledge, and data that could ultimately be the answer for affected babies and their families. Imagine the potential for innovation of therapies, pharmaceuticals, and medical devices!

But without robust patient input, data loses its humanity, its quality. The power of the patient's story adds nuance, critical wisdom, and attaches real faces to the issue. These pearls provide research projects with an opportunity to shift from pragmatic study to a fully evolved, 360-degree view of the disease state, directly from the lens of the patient. What we know from the literature is that patient-centered research gives way to improved clinical practice, stronger therapeutic drug development, and innovative solutions aimed at supporting affected individuals and their families in reaching their goals. At the forefront of neonatal practice, we must remember that medical and clinical innovation is fruitless if we do not understand the human value.

To date, many disease communities have benefited from this type of "deep dive" patient registry: from Alzheimer's disease to rare cancers and even Cerebral Palsy. Yet, with the exception of one robust registry (The Morgan Leary Vaughan Fund's Necrotizing Enterocolitis (NEC) Registry), prematurity has not had the infrastructure in place to collect patient data in survey questions, oral history, or video collection. With so many health variables and disease states affecting premature infants, there is a rampant opportunity to gather better data, not only for researchers and health professionals but also for the patients and families they serve.

Imagine what knowledge we can gain by understanding the human and family experience behind the NICU: premature birth outcomes—with multi-pronged ailments leading to either life-long disabilities or even death—has yet to bring about an explosion of therapies targeted at these tiny infants. With the vast majority of neonatal drugs never being studied in low birth-weight infants, we still have so much left to learn. Our babies, families, and neonatal providers deserve better data, faster drug development, effective implementation of evidence, and—ultimately—answers and solutions for families.

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So, imagine for a minute how we could grow the power of the patient and unleash the potential of medical research through an online, international patient registry on prematurity. In traditional research settings, neonatal sample sizes average 10-1,000 patients, even though 15,000,000 premature infants are born around the world each year. (1) These samples only begin to tell the real story. The depth behind patient-entered data could add a rich set of endpoints and incredible ideas for innovation that incorporate medicine with real-life implementation. Imagine if instead of concluding manuscripts with the ever-elusive, "more research is needed," we could truly learn more about the science from the holistic lens of the patient and families experience it, and effective provider solutions to support families and communities through next steps. It is not outside of our reach.

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Working collaboratively with the parent and neonatology community, PreemieWorld is embarking on a community-wide global patient registry of its own. The registry will transform research through the ability to include patient-focused data, improve recruitment and diverse participation, and increase the ability to study outcomes data in real time while connecting the patient connection to foster community and decrease isolation. The NICU stay is critical, but prematurity’s focus is not entirely on birth; it spans the life course. With more than 15,000,000 babies born too early each year, we have a rich cohort of teens, young adults, and older adults living out the outcomes of prematurity and contributing to critical wisdom for better solutions. It is time that all stakeholders benefit, from neonatal researchers to industry leaders and patients and families. Stay tuned for an update from PreemieWorld on registry progress in the coming months.

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Disclosure: Deb Discenza is the founder and CEO of Preemieworld. Andrea Schwartz Goodman has no relevant disclosures.

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Corresponding Author:

Deb Discenza
Founder and Chief Executive Officer
PreemieWorld
www.PreemieWorld.com

Andrea Schwartz Goodman
Senior Editorial Project Director
Neonatology Today
Andrea.SchwartzGoodman@NeonatologyToday.net