



1 What motivated you to launch your organization?

My daughter was born prematurely over five years ago. After navigating the difficult NICU (Neonatal Intensive Care Unit) journey, I realized that although there are many wonderful Jewish organizations serving families facing medical hardships, there were no resources to specifically help families of premature newborns. My entire family felt an amazing sense of gratitude to Hashem that my daughter had survived this ordeal and has no long-term effects as a result of her prematurity. With the support and encouragement of my husband and children, WeeCare, a non-profit organization, was founded.

All of the co-founders of WeeCare had experienced similar situations and were motivated by their own personal journeys with a micro-preemie (see sidebar).

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10 Questions for:

Chana Rivky Weinberger
Founder of WeeCare



WeeCare, which was established in the fall of 2017 to support families of premature babies in a myriad of ways, has had the zechus of assisting over one hundred families before reaching its two-year anniversary.

What is your current role at WeeCare?

WeeCare's amazing group of co-founders — Rifky Amsel, Shaindy Felder, Chanie Greenspan, Chanie Groner, Toby Tabak, and I — have each invested much time, talent, and resources in our organization. Each one of us is a mother or grandmother of a preemie (or preemies!) and genuinely understands the need for practical and emotional support, as well as the variety of services essential for families of preemies.

Each family of a premature baby that would like to accept our services is assigned a WeeCare representative, each of whom has had their own preemie. Based on their preference, we may be in touch with the parents by text, phone, or email; daily, on a weekly basis, or only when they reach out to us. Some families are hap-

py to take any services offered, while others refuse multiple times before they accept. Some would prefer to deal with the challenge without accepting help or they just don't have the headspace for outside involvement, and we respect that. Each personal rep will work with the family based on their specific comfort level.

Of course, we respect the privacy of the families and do not divulge information to anyone, including a client's own family members who may reach out to us. People are well-meaning, but WeeCare waits for the mother of the baby to initiate contact and only provides the services she requests, not those that a family member thinks she needs.

WeeCare's co-founders were trained in several areas by a highly regarded social worker, including guidance on how to sense what the family needs, without prying.

3 What is one great challenge you face in running the organization?

Our greatest challenge is assisting each family in a way that works for them. In general, families tend to handle medical situations differently. While prematurity is usually not a secret, the specifics of a baby's condition may be something the parents choose to share or prefer to keep quiet. According to the preferences of the family, we offer support in a way that works best for them.

Another challenge is regularly hearing about members of Klal Yisrael dealing with pain, difficulties, and struggles. It's a balancing act to be encouraging and supportive but understanding that we cannot assure a positive outcome, since each child has a different experience destined for him, and Hashem is the One who runs the world. I try to keep this perspective and I take encouragement from the many happy conclusions, baruch Hashem.



4 Can you highlight the different aspects of the work you do?

With each situation, we continue to learn about new avenues for helping families of preemies.

A key goal of WeeCare is peer to peer support. There are countless questions and concerns that are addressed. After so many conversations, relationships are developed; it's no wonder we call it our WeeCare family!

We are available to speak to preemies' parents and more importantly, to listen. We understand the challenges; we understand the victories. For instance, when a preemie is allowed to wear an undershirt for the first time, it is a huge milestone. (This usually means that the medical staff no longer has to watch his chest to ascertain whether the baby is breathing properly and that the baby can maintain his own temperature.)

We try to address different aspects of each situation. Therefore, a rabbinical board which understands the nature of the preemie community was set up to guide us whenever needed; and the organization has recruited an amazing team of medical professionals who have made themselves available to speak to the WeeCare founders or parents of preemies, as required.

As far as services we provide, our list is constantly growing. Door-to-door rides for mothers of preemies are provided by our wonderful volunteers, because we understand that a Bikur Cholim shuttle or public transportation may not be the best mode of transportation for a new preemie's mother. (She is often post C-section, carrying expressed milk, and is certainly very stressed. Testing and urgent issues that arise also complicate schedules.) Delicious homemade suppers are cooked and delivered in many neighborhoods. This is sometimes done in larger quantities so one merely needs to rewarm the meals upon returning from the hospital. Clothing, books, and other various other items are available.

Prepared with care, a sweet welcome package as well as a discharge package, are sent to the families of these babies. The packages contain both practical and feel-good items.

Recognizing that siblings of preemies also need extra care as well, we give them extra attention and often send gifts with a letter from other siblings of preemies to "welcome them to the club" and help them feel understood. WeeCare even printed special stickers that read, "I am a proud sister/brother of a preemie!" It can be so challenging when parents are busy with a baby in the hospital and the children of all ages can be worried, lacking routine, and/or dealing with additional responsibilities.

We're also available to speak to grandparents or other family members to guide them on how to help the preemie's parents they love.

We've had much *siyatta diShmaya* in establishing a weekly phone support group moderated by a Lakewood-based therapist, Goldie Schechter, which provides valuable support to mothers of preemies. Some mothers are active participants in our phone group, and others prefer to listen in and remain silent. In recent months, a text group was started for WeeCare mothers exclusively about prematurity, and already, so many have made connections or provided key information for another mom experiencing similar circumstances. These groups, as well as the biannual brunch we host for mothers of preemies, allow for engagement and camaraderie with other preemie families.

Our website includes resources such as medical information, *chizuk*, questions for preemies' parents to ask a Rabbi, and advice on how to advocate for a preemie baby. Lists of minyanim and kosher food available near hospitals are provided as well. Additionally, we're looking forward to a fresh update for our website in the near future.

Most importantly, there is a *tehillim* list that we send out to our text group every Erev Shabbos with the names of our preemies, many of them still going by just *tinok*.

Each preemie situation is so unique; each set of circumstances warrants differing services. So in fact, with each new call, we consider novel ways to assist these families.

5 Can you share a positive story that you've recently experienced?

WeeCare has been involved in many miraculous prematurity journeys. We were privileged to have helped the family of the earliest surviving preemie in a major NJ hospital, born at a very early gestational age and at a very low birth weight — she was considered to have a 1% chance of survival! She is now a delightful 1½-year-old, baruch Hashem. It gave us great joy when this baby was discharged, breathing on her own, having reached regular milestones.

6 What do you wish people would know about prematurity?

Many people have not and will never be exposed to prematurity. When a friend or family member delivers prematurely, they want to be supportive, but often have no idea what the parents are dealing with. Many people think it's merely a waiting game until the baby weighs enough to come home, or they'll assume that the baby must be "so cute and tiny."

Preemies are not just "mini babies." They may spend weeks or months on a respirator and in an incubator, limiting contact between parents and their precious baby. Mothers will likely find it difficult to imagine a scenario where they're home without their newborn and cannot hold their baby for an extended period of time.

A premature baby may be born with translucent skin and need breathing or feeding assistance, as well as being at risk for brain bleeds, bowel perforations, lung disease, cardiac conditions, and many other issues. Concerns arise with vision and all aspects of development. Functions and skills that normally develop in utero must be learned in the NICU. Most people don't realize the extent of the issues that accompany a premature birth; the list is beyond the scope of this article. The care needed, the technicalities and decisions involved are all-encompassing. Medical and developmental concerns need to be addressed post-NICU as well.

Certain situations are more "typical preemie" while others are not. I never know what we'll be dealing with on any given day! But WeeCare is open to helping all, and if for any reason we are not equipped to assist, we've established connections with many others who can.

7 How do the services you provide today compare with your vision when you first launched the organization?

While we recognized the need for an organization serving families of premature babies, there are a few things that were not anticipated.

Originally, we'd considered an advertising budget but word spread fast and the number of preemie families we've been privileged to help quickly grew without even one ad. Also, the response to our text group and weekly conference was overwhelming.

We understood that families of preemies would benefit from our new organization and its services, but we did not anticipate the need for continued emotional and technical support for parents of NICU graduates. Having a premature baby often results in long-term health issues, as well as dealing with the ramifications of the trauma experienced by the family.

WeeCare clearly fills a need in the community, but we were somewhat surprised by the encouragement we received from other national Jewish organizations who recognized that the needs of preemie families were not being met sufficiently.

In preparation for the launch of WeeCare, we focused on what we'd need to do to support mothers of preemies. What we hadn't realized was how their strength and fortitude would never cease to amaze us. Personally, a side benefit for me is getting to know all of these incredible mothers.

8 What's the best part of your work? The toughest?

The best part of our work is sharing in the joy families experience at every milestone. It is also very rewarding to see how WeeCare has evolved into not only an organization, but a warm community where individuals support one another and develop relationships.

Another perk is that while WeeCare was established to help others, all of the founders are constantly inspired by the families we encounter! Attending *brisim* and *seudos hoda'ab* for premature babies gives us immense pleasure. We rejoice with WeeCare families, since we truly understand what they've been through and the miracles they've experienced.

On the other hand, it's challenging when these precious babies have to face long-term challenges. The toughest is when, unfortunately, a premature baby does not survive. WeeCare tries to help the parents to navigate the heartbreaking *nisayon* of losing a child.

9 How do you manage the stress that comes along with your taxing work?

It's true that it can get stressful, but I try to focus on the needs at hand and the privilege of helping others after what I've been through. Truthfully, it can become especially stressful to "hold the hand" of a mother of a preemie when her baby is critically ill. Occasionally, I find my heart racing with hers as we await the results of a test or the outcome of a surgery. Sometimes, I will hear that a family was told to stay close to the hospital because their baby's condition is so critical.

As the founding team, we support each other and are always employing different strategies for coping. I do try to remind myself that I can be more supportive while in a calm, relaxed state. Additionally, while we try to make ourselves available whenever possible, particularly because these situations are so delicate, sometimes it's necessary for us to push off dealing with a matter until we're able to take care of it. Boundaries are important because they enable us to keep on with our work.

Really, we could never have accomplished all this alone. Currently, we have a volunteer base in each of the following locations: Brooklyn, Lakewood, Monsey, Queens, and the Five Towns. These devoted volunteers freely give of their valuable time, are supportive of the mothers we work with, and often form long-term relationships with preemie families.

We also share *chizuk* messages with each other, whether from Torah sources, or a preemie news story with a happy ending.

10 What was the best feedback you've ever received?

We always appreciate feedback! It helps us grow and continue to help others. While we've been involved in all types of scenarios, one oft-repeated comment is, "All of the little things you do make a huge difference!"

Along with that, we are privy to incredible Hashgachah stories, which, on a number of occasions, were connected to WeeCare. For example, one Wednesday night, one of our preemie moms was so frazzled because her baby was coming home the following morning. Although she's a regular participant in our conference call, she wasn't sure she had the time or the wherewithal for it, but called in anyway. That night, the prepared topic was all about the emotions that might be experienced when a preemie is finally ready for homecoming.

Interestingly, volunteers often thank us for the opportunity to help others, allowing them to participate in such an organization. They share how they've been inspired and have grown through their connections with our preemies' mothers. ♥

If you would like to avail yourself of WeeCare's services, volunteer, donate, or make an inquiry, please call 732-813-3299 or email weecarepreemies@gmail.com.

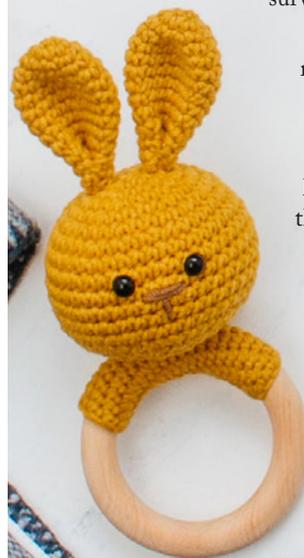
Ten percent of babies in the United States are born prematurely every year. A premature baby is defined as any baby born before the 37th week of pregnancy. A small percentage of preemies are considered micro-preemies, usually babies born at less than 26 weeks gestation or 800 grams (1 pound, 12 ounces). While any premature birth is stressful for the family, the birth of a micro-preemie is incredibly daunting. Under 50% of babies born under 25 weeks survive. The survival rate increases with gestational age, and the survival rate for babies born at 27 weeks is 80–90%.

Unfortunately, prematurity is the leading cause of neonatal death. In the last few decades, technological advances have much improved the outcome for premature babies. As recently as the 1970s, when a baby needed breathing support, which is now given by a respirator, the nurses needed to manual bag him, only stopping when they had another nurse to relieve them.

Incubators, temperature-controlled enclosed cribs are only about 50 years old. The first incubators were built by Dr. Couney, a French physician who used them as a freak show in Coney Island, NY. He had nurses caring for very small babies and would charge 25 cents to view the tiny babies. He paid for his research with the cost of admission and was mocked by most of the medical community. However, by the 1940s, he had many surviving preemies to his credit and had earned respect among doctors. It was only then that incubators were introduced in mainstream hospitals. Since then, there have been many medical advances that have greatly improved the chance of survival for preemies.

In many cases, if there is any reason to expect an early delivery, the mother will receive steroid shots beforehand in an attempt to strengthen the lungs of a preemie prior to their arrival.

In the 1990s, surfactant was approved by the FDA. Surfactant is a medication administered to help prevent lung collapse, and has helped increase a premature baby's chance of survival.



Mrs. Rifky Amsel is a veteran mechanic and former principal, and is currently an educational consultant and writer in Lakewood, NJ.