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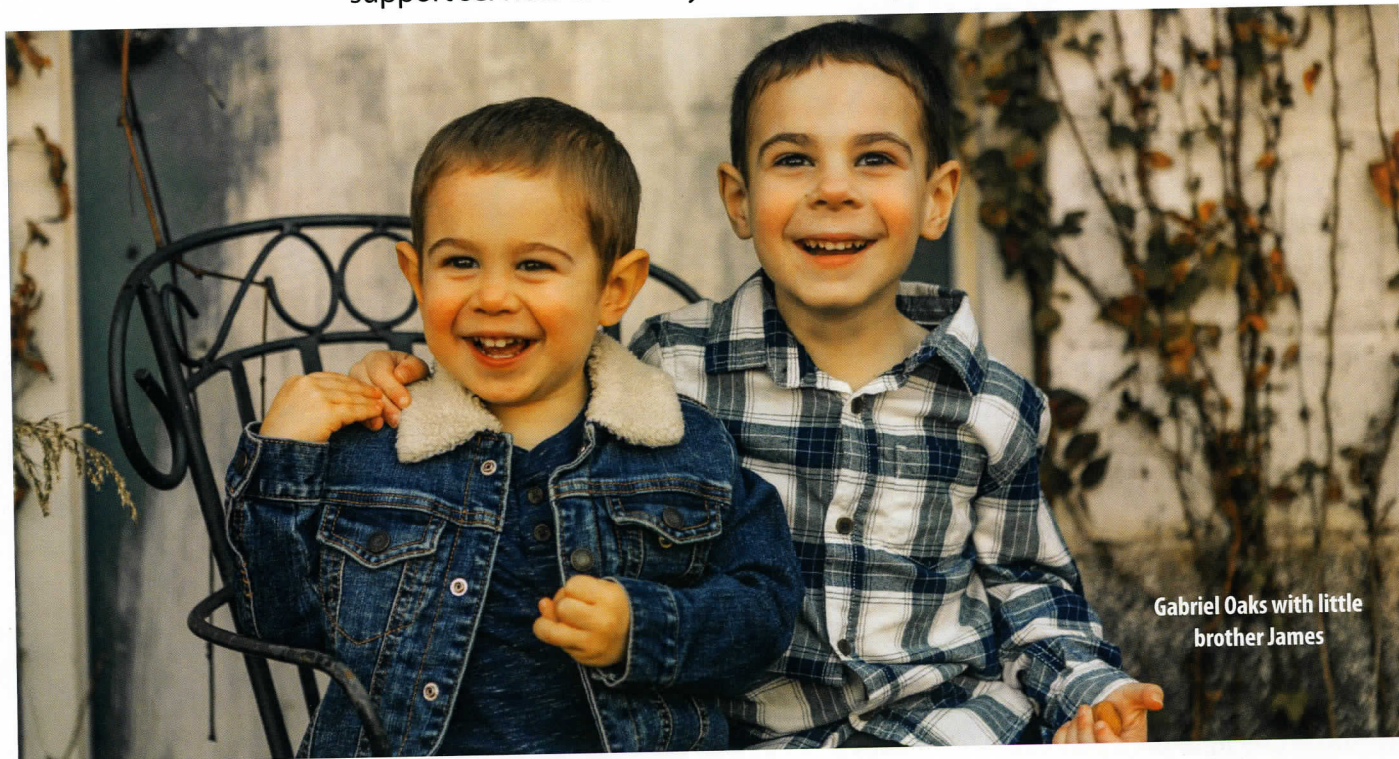
Special Programs for Special People

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Gabriel Oaks with little brother James

PHOTO: Travis Ilapit

It is no secret that military service can be tough on family life: regular deployments separate spouses from each other and their children; frequent moves can upend normal routines and support networks; and demanding schedules can wreak havoc on child care and spousal employment. Add to these ordinary stressors the challenges of having a family member with extraordinary needs, and it can turn life in the military into an arduous, exhausting, and grueling trial.

But fortunately, here is hope...and help, in the form of the U.S. Department of Defense's Exceptional Family Member Program (EFMP.) Service members on active duty are enrolled in the EFMP when they have a family member with a physical, emotional, developmental, or intellectual disorder requiring specialized services, so their needs can be considered in the military personnel assignment process. The EFMP coordinates its services with other military and civilian

agencies to provide comprehensive and coordinated community support, housing, educational, medical, and personnel services to families with special needs.

It can be somewhat of an uphill climb to identify and enroll an exceptional family member, current military families relate. "Everything can feel very overwhelming and unknown when you are a military family," notes Rebecca Macomber, whose husband is a U.S. Navy Chief Petty Officer. "Adding on top of that an exceptional family member and the pressure can sometimes feel like too much to handle." The Macombers have a four-year-old daughter, Hannah, who has cerebral palsy.

"The best advice I can give is to just take a step back and evaluate what is most important to you," Macomber notes. "You might not be able to do it all. And that answer won't be the same for everyone."

Another Navy spouse, Lauren Oaks, comments, "It is really hard at times. Every time we move, I have to find all new doctors – pri-

mary care manager, gastro-intestinal, surgeon, endocrinologist, ENT (ear-nose-throat), and speech therapist." Oaks and her husband, Kyle, a Naval Petty Officer First Class, have a son, Gabriel, with hyper motile long segment Hirschsprung's disease; he had his first surgery when he was just three weeks old.

"Gabriel's had seven surgeries and been a patient at eight different hospitals," Oaks explains. "Every hospital has different protocols and a different way of handling everything, so each time, we are starting from scratch. Gabriel's surgical team is in Washington, DC, so I have to jump through hoops to get them approved with each move as well. Thankfully, Kyle has not deployed since we had Gabe. I don't know how I would be able to take care of everything for Gabe on my own – physically and mentally."

Both women say that it can be difficult for other people to understand what they and their families are experiencing. "Your friends with 'normal' kids will never understand," Oaks

declares. She adds, "Try not to get too frustrated with them because it will only wear on you. They will complain about their baby waking up 'all night long,' but they will never understand what it is like to spend more nights in a hospital room than in your home during your child's first year of life. Your family will never understand. Someone will always tell you 'it could be worse.' Your feelings are justified; feel it all; get sad and angry. It can be very isolating, but it doesn't have to be. Find someone who understands what you are going through."

"Gabriel's diagnosis has truly brought my husband and I closer together," Oaks continues. "We've had to lean on each other because no one else can even come close to understanding the exact hell you are going through. Moving away from family/friends also forced us to lean on each other. That has made us stronger as a team and stronger as individuals. I also really appreciate the military family that we've created. Our military family is more reliable."

Macomber says her husband has chosen to geo-bach, short for "geographic bachelor," an unofficial slang term used when a military family chooses to live in a different location from the service member. "You may have to prioritize keeping your exceptional family member's care consistent or living together as a family," she explains. "We are so lucky because Hannah is very adaptable and has a go-with-the-flow personality. However, due to all of her appointments and doctors, we have chosen to geo-bach while my husband is on sea duty. Luckily, he is only a three-hour drive away, so he comes home every weekend when he isn't deployed."

Both families are part of the Exceptional Family Member Program. "Gabe has been in the EFM Program for over three years now," Oaks says. "It has narrowed down where Kyle can be stationed, so Gabriel has to remain near a level 4 (out of 5) children's hospital. I'm told it is not a guarantee, but we haven't had any issues."

"Even with Kyle 'home,' he is not really here to help, so everything gets put on my shoulders," Oaks continues. "Gabriel takes multiple medications every day, including a high volume enema every night. His medications are constantly changing as he grows, so I am constantly reaching out to his surgical team to adjust them. Too little, and he has accidents all day long. Too much and I constipate him too



Hannah Macomber with twin sister Makenna

much, and he ends up in the hospital. He constantly has doctors' appointments; he also has hearing loss in one ear and apraxia, so he is in speech therapy three times per week. Very rarely is Kyle able to help with any of that."

She adds that Gabriel also is enrolled in the Extended Care Health Option (ECHO) that provides financial assistance to EMFP beneficiaries with special needs for an integrated set of services and supplies, including diapers, wipes, and special barrier films to protect his skin. The Prime Travel Benefits Program can also help with travel costs incurred when traveling for appointments.

Macomber experiences similar struggles: "Hannah has lots of appointments each week. She has OT twice per week and speech therapy once a week. In addition, every month it seems she has appointments for her other regular doctors. She has food allergies, a neurologist, a developmental pediatrician, an eye doctor plus all of the regular dentist and doctor appointments. She also goes to a special education preschool for a full day Monday through Friday. Fitting that all in each week is a big challenge."

"Because Hannah is an EFM category four with the Navy, she is eligible for respite care each month," Macomber continues. "That means she gets 40 hours of care each month paid for through the program. That is a huge help because it gives me to time to run errands, go food shopping, or just have some me time."

Macomber also has a neuro-typical daughter, Hannah's twin sister, who has her own schedule. "It's a lot of coordinating schedules to make sure that they are both able to get to where they need to be each day," she points out.



The Macomber Family

The military has a dedicated website, EFMP & Me (<https://efmpandme.militaryonesource.mil/about-us>), to help families understand and access the services for exceptional family members. The website includes an interactive tool to provide 24/7 access to information and resources for service members and families, service providers, and military leaders.

Oaks advises other military families to explore all of the services available to them through the EFMP. "Advocate for your child and yourself," she asserts. "Get second opinions. Be proactive. Question everything."

Macomber suggests families work closely with EFMP case liaison to determine eligibility for various programs. "There are so many programs and benefits that are available, and it's impossible to know about them all by yourself so be sure to speak with your case liaison and use them as a resource."

"If possible, form a tribe at whatever duty station you are at," Macomber adds. "They can help you with childcare or rides or just having someone to talk to. It is nice to have a few good friends who you know you can count on." 🇺🇸