

Media Release

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KIDS MAKE ALL STAR TEAM AGAINST ALL ODDS

July 20, 2004 ROCHESTER, N.Y. – Nicholas and Andrew Dedman are two bright, active and talented kids who made their divisional All Star Baseball Teams. If you ask them, they will tell you that making the teams were highlights in both their lives. Nick is 12 and plays for the Batavia Blue All Star Little League team and Andrew who is 16 made the Batavia All Stars Senior League team. What is truly impressive is that both boys, like their grandfather, have severe hemophilia.

Hemophilia is a hereditary bleeding disorder, primarily affecting males. People with hemophilia are missing or deficient in certain proteins in the blood, called clotting factors. This results in blood not clotting properly and people needing medical intervention to stop a bleeding episode. Internal bleeding into the joints poses a major problem for people with hemophilia, and this can be caused by a slight bump, jolt or can even begin spontaneously for no apparent reason. Hemophilia is usually treated by intravenous infusion of a replacement clotting factor. Without treatment, hemophilia can cause crippling pain, severe joint damage, disability, and early death. Some people infuse clotting factor on a preventive basis while others on an “as needed” basis when bleeds occur.

When Andrew was born in 1988 he was diagnosed with severe hemophilia. His parents, Barb and Bruce Dedman were told that he'd always have to be kept in a very protected environment to avoid unnecessary bleeds. He wouldn't be able to run, jump and play like other kids and certainly never be allowed to participate in sports. Barb recalls being instructed by doctors at the Mary M. Gooley Hemophilia Center, “Get rid of all furniture in your house with pointy ends – coffee tables, end tables and night tables. Pad all your window sills so that Andrew won't hit his chin. Once he starts crawling and then when he learns to walk, make sure he wears knee pads, elbow pads and a helmet!” None of this was shocking to Barb. She had grown up with a father who also suffered with severe hemophilia.

“Medical advances have changed all that.” says Robert Fox, President and CEO of the Mary M. Gooley Hemophilia Center. As leaders in the field of hemophilia for over 50 years, we've been able to take advantage of all the innovations and scientific breakthroughs to ensure that the quality of life of our patients is much better today than even a generation ago. Our Center provides cutting-edge care to all of our patients through a proven, comprehensive family-centered approach delivered by a team of highly-trained nurses, social workers, hematologists and specialists.”

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“We have been so fortunate to have the Mary M. Gooley Hemophilia Center taking care of our sons,” Barb says. “Life is so much better for our kids than for my Dad. He grew up not able to do any activities. I’m told that he’d sneak out once in a while to play pick-up football and then be in bed for weeks suffering – sometimes at home and other times in hospital.”

Both Andrew and Nicholas do prophylactic treatments at home for their hemophilia. Three times a week, Andrew infuses his veins with special “Factor” and Barb infuses Nicholas - except when they’re playing baseball and then they do the infusions before every game and practice. Nurses at the Mary M. Gooley Center trained the Dedmans to do this at home so that the boys could participate in baseball and so that the family could go on vacations and not feel tethered to the Center. “The independence that this has given our family, is truly a blessing,” says Barb with tears in her eyes.

Andrew’s team has made it to the ‘playoffs’. His Mom proudly brags, “In his first all- star game last week in Leroy, he got 2 hits, 4 RBIs and his team won! Andrew plays in the district championship game tonight and if the team wins they go on to play in Penfield on Saturday, July 24.

Nicholas plays shortstop and pitches. He has pitched several no hitters and one perfect game. Last Tuesday, he pitched a one-hitter leading his team to their district championship victory. Nick helped himself at the plate going 2 for 3 with 2 RBIs and scoring 2 runs. He also struck out 12 batters making him virtually un-hittable. Nick won the sportsmanship award in Little League this year and also was awarded the Effort and Courage Award for 6th Grade in his school. In most respects, Nicholas is just a regular kid. According to him, his greatest dream is to meet Cal Ripken Jr! What is especially heartwarming is how wonderfully supportive and unselfish the kids on the team are. According to Nick’s Dad, who coaches the team, “When Nick was hit by a rock on his temple – the kid’s clearly were more worried about Nick and his hemophilia, than his having to leave the game. That says a lot for kids in the middle of a championship run!”

The Dedman Family is remarkable in the positive attitude they project. To them, the proverbial glass is always half full. But there’s still a huge downside to hemophilia - there still is no cure.

Any surgery poses a serious bleeding challenge to people with hemophilia as does dental work, or any strenuous activity or contact sport. Poking needles in veins is not a pleasant task – neither for Andrew or Nicholas, nor for Barb and the many others like her having to do this on an ongoing basis to those they love. Andrew’s elbows won’t take the stress of basketball which he’d dearly love to play and his parents always worry about the next generation of kids, and which ones will be burdened with the hemophilia gene. And even though hemophilia was known for many years as the ‘Royal Disease’ because it appeared in the offspring of Queen Victoria of England and then spread to several other European royal families through her descendants, hemophilia patients certainly don’t feel like royalty because they carry these genes. But according to Barb Dedman, “The Mary M. Gooley Hemophilia Center has been incredible to us – they treat us like royalty!”

The Rochester Hemophilia Society was established in 1949 and the Mary M. Gooley Hemophilia Center opened in 1959 as the first free-standing comprehensive treatment center for hemophilia in the United States. The mission of the Mary M. Gooley Hemophilia Center is to improve the lives of people affected by bleeding disorders and iron overload. This is done using a comprehensive model of care in which quality of life issues are closely monitored. In addition to its extensive research projects, Center staff treats patients with Hemophilia, Hemochromatosis (iron overload), von Willebrand Disease and Gaucher Disease.