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Cystic Fibrosis patients have a new casue for hope

By Ellie Bigue of The News-Sentinel
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Matthew Cox was six weeks old when he was sent to Riley's Hospital for Children with pneumonia. It was only then that he was diagnosed with cystic fibrosis. Doctors believed he would only live to be a teenager.

Now 23 years later the life expectancy for CF patients is 37. Bruce Cox, Matthew's father said Cox is thriving and a recent new drug has dramatically changed his life. Kalydeco is a drug that works as a transmembrane conductance regulator. In other words it opens the door to cells to allow chloride in.

Cox said his son will always live with the damage his lungs have suffered up until now, but his hope is with the new drug there will be no new damage. For children born now who can take this drug, explained Cox, may never suffer from the life threatening complications the disease causes.

According to the website of the Cystic Fibrosis foundation, CF is caused by a defective gene that causes the body to produce a thick mucus. The gene causes a malfunction or total lack of CFTR protein. Mucus clogs the lungs causing infections, and obstructs the pancreas, which keeps the body from releasing the enzymes that help break down and absorb food. Around 30,000 children and adults in the United States are affected by this disease, 800 here in Indiana.

More Information

VIP tickets are $250 ($180 is tax-deductible)

Main event tickets are $55 ($27 is tax-deductible)

To purchase tickets, call (317) 202-9210 or visit: Indiana.cff.org/ftwaynewine.

People who have CF must go through daily treatments to loosen the mucus from their lungs, as well as do numerous breathing treatments, and take synthetic enzymes to help with their digestive track. Putting on weight and keeping it on is always a challenge.

Annie Lickliter, who has two teenage children with CF, Carly Lickliter, 15 and Park Lickliter, 18, said because it only effects a small percentage of the population less research is being done. It wasn't until 1989 that the gene that causes CF was discovered. Once that was discovered it was a race to develop drugs that could counter the gene's effect on the body.

Since the recent success of Kalydeco, which allows 4 percent of the CF population to lead a more normal life, there is optimism that more drugs will soon be approved. According to the Cystic Fibrosis Research Inc News, currently the makers of the drug, Vertex, have plans to begin testing several other drugs that could help a broader segment of the CF population. Since 2011 the CF Foundation has been working in collaboration with Vertex, investing up to $75 million over five years to speed up the development of drugs that attack the underlying cause of CF.

This Saturday night the Indiana Chapter of the Cystic Fibrosis Foundation will be hosting their 9th annual fundraiser in the Tower Bank lobby. Lickliter, chair of this year's event committee said 90 cents of every dollar raised there would go towards more research. Last year the group was able to raise $110, 000 from the evening.

The event, Lutheran Health Network Wine Opener is presented by the Mary Cross Tippmann Foundation; there will be a VIP reception from 5:30-7:00 p.m. with entertainment provided by Kyrou's Music Studio. The main part of the evening will take place from 7:00-10:00 p.m. VIP tickets are $250 ($180 is tax-deductible) and main event tickets are $55 ($27 is tax-deductible) with all proceeds benefiting the Indiana Chapter of the Cystic Fibrosis Foundation. All food and drink are included in the ticket price. There will also be a silent auction.

The Cystic Fibrosis Foundation, a nonprofit donor-supported organization, is to assure the development of the means to cure and control cystic fibrosis and to improve the quality of life for those with the disease. For further information about cystic fibrosis or Lutheran Health Network Wine Opener, call (317) 202-9210 or go to http://indiana.cff.org/ftwaynewine.

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