

# Who is Eliza Banicka and why she needs our help

Eliza Banicka a cute 15 year old with red pigtails suffers from Niemann-Pick Syndrome. The same disease that took the life of her older brother Michal.

Adding to Eliza's parents anguish is the fact that the only available medication, Zavesca is not covered by the national health insurance in Poland. And its cost is beyond the reach of an average citizen – it's about PLN 12000 a week (\$3750)! So a group of people – most of them never saw each other in real life – gathered together over various social media in a desperate attempt to save little Eliza.

Other than lobbying the politicians and spreading awareness in the media, they started a spontaneous action of making rag dolls that would be sold online on Allegro.pl (a buy-and-sell portal similar to eBay) with all proceeds going to cover the cost of Zavesca.

At the same time they have been advertising it on Facebook and throughout other on-line communities. The group established The Red Pigtails Day on March 16th which is Eliza's Birthday as a gesture of solidarity with the victims of N-P Disease. Posters and flyers started circulating with the more and more familiar face of the little red-headed girl in a pink t-shirt. As the politicians were reluctant to offer solution the ordinary people reached out to help. <http://www.facebook.com/-LalkiDlaElizy>

The first dolls barely made it to their new owners when the snowball effect started rolling throughout Poland. Little town community centers and big city halls, actors, musicians, children book writers, schools, including the boarding schools for mentally and physically challenged children, as well as

the local libraries and even the inmates of the correctional institutions – Eliza has touched everybody's heart.

Some of the dolls are meticulously finished and dressed, some are a little crooked, some show a pretty rough stitch work but every single one of them has a little heart sewn inside, a name and a life story given to her by her or his creator. Moreover, people begin to feel that they help themselves by helping this little ill girl.

The dolls help in many ways. They help those who make them – the inmates, the disabled, the elderly who often feel they themselves are a burden to the society. Some dolls after the auction are being sent to the Children's Hospice in Wrocław – they bring smile to the little patients in their final weeks and days. And, of course the proceeds help the Banickis purchase Zavesca.

There is also a group of traveling dolls <http://www.facebook.com/LalkiPodrozuja?fref=ts>

They go to the local markets and to the towers of Dubai, they fly to Israel, Toronto and Cuba. They “talk” about Eliza and her dire situation. Because as noble and widespread the efforts are, Eliza's fate is still very grave unless the government starts to listen. 12 thousand dollars a month is an unreachable amount month after month, after month... But for now, until the Government wakes up new posters are showing up in different cities inviting people to bring their sewing machines and smiling faces to another doll-making event and the dolls keep sprouting up in every part of Poland.

**Please support us in our efforts to finance the treatment and rehabilitation of our daughter.**

Niemann-Pick Disease, Type C is an inherited disorder which attacks the brain and leads to gradual loss of all biological

functions. Eliza's older brother, Michał, also had this disease. He first lost the ability to walk, speak and swallow, then he had problems with breathing and eventually... he died at the age of 14. Our daughter Eliza shows such symptoms as shaky hands, difficulties with walking and speaking and loss of concentration. Since September 2009, she has been taking a drug which has helped keep the disease at bay. The neurologist confirms that it has significantly benefited her health and the medical parameters have improved. However, there are still serious problems with her condition. The only drug available, which has been approved and registered by the European Commission since January 2009, Zavesca (Miglustat), is not refundable by the Polish National Health Service. At present, it costs about PLN 12000 a week (\$3750). On top of that, Eliza needs rehabilitation to stay self-reliant. We cannot afford to pay for it all by ourselves, and therefore we urgently need your support.

We are thankful for all the help we have received so far. It has been a real blessing and has helped us not to give up hope. Yours sincerely,

[Daria](#) and [Dariusz](#) Baniccy (Eliza's parents).

If you wish to become a donor and help with Eliza's treatment and rehabilitation, please transfer your contribution to the account of the "Bread of Life" foundation:

Fundacja "Bread of Life"  
Długa Goślina 1,  
62-095 Murowana Goślina

Bank account IBAN: 'PL 12 1940 1076 3023 5096 0001 0000'

SWIFT (BIC): 'AGRIPLPR'

Bank name: 'Crédit Agricole'

Bank address: 'pl. Orłąt Lwowskich 1, 53-605 Wrocław, Polska'

Please add a note: 'pomoc dla Elizy Banickiej'

You can also use your Credit Card or PayPal account:

Donate



## About Niemann-Pick Disease

Niemann-Pick Disease is a rare inherited disorder, with only a couple hundred ill children in Poland and ... worldwide. The disease affects the management of fats in the body, causing harmful amounts of lipids to accumulate in spleen, liver, lungs, bone marrow, and brain. This leads to gradual phasing out of the functions necessary for life. Such ordinary activities as walking, talking, swallowing, and eating become an ordeal. The progress of the disease can be effectively hindered only by appropriate medication.

For more information about this disease, please follow the link:

<http://en.wikipedia.org/wiki/Niemann-Pick> or visit  
<http://www.niemannpick.org.uk>