

Financial Sources of Polish Haemophilia Society's Activities

Bogdan Gajewski
Polish Hemophilia Society



Haemophilia and the Polish Haemophilia Society

Haemophilia is a one of rare diseases: the current population of people with haemophilia and other congenital bleeding disorders in Poland is estimated at about 4500. Polish Haemophilia Society has about 1600 members – they are pwh and their relatives.

PHS is a very efficient organization, actively struggling for an improvement of haemophilia treatment. It has been many times stressed by representatives of the MoH that despite being a small group of patients we are one of the most active patient organizations in Poland.

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Polish Haemophilia Society's Activity

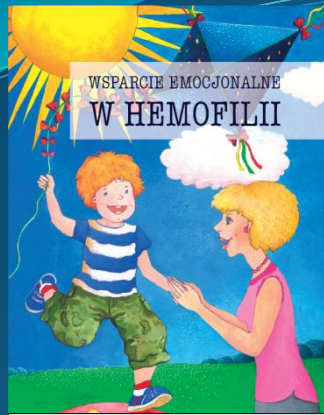
The main aim of the PSH is an improvement of haemophilia care, which used to be very poor for many years; one of the visible effects of this awful past is that most Polish adults with haemophilia have considerable joint deformations. Thanks to PHS's actions Poland has now prophylaxis for all children and youths up to the age of 18 and a National Haemophilia Treatment Programme for adults.

PHS organizes meetings and workshops for pwh and their families with participation of doctors, physiotherapists and psychologists. It regularly organizes press conferences on World Haemophilia Day and publishes books, CDs and DVDs on haemophilia and haemophilia care (most of them being translations from English). So far 24 books, 7 CD and DVD titles, and also several posters, a game for children and a haemophilia medical card have been published. We have supplied physiotherapy equipment for several haemophilia rehabilitation wards. We have also provided financial support for purchasing medicines to several pwh who could not afford such expenses.

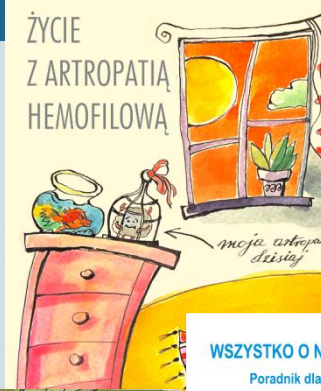
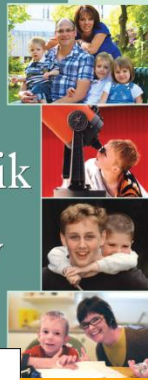
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Polish Haemophilia Society's Activity



Wszystko
o hemofilii
Poradnik
dla
rodziny

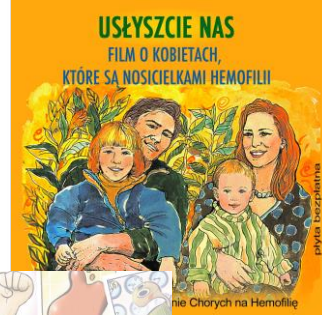


JAK WYBRAĆ
OPIEKUNKĘ I PRZEDSZKOLĘ

Przewodnik dla rodziców
dzieci chorych na hemofilię



Operacje
ortopedyczne
u chorych na hemofilię

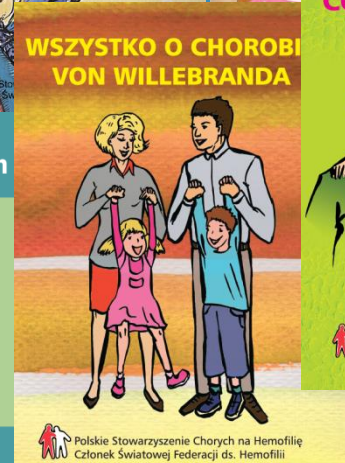


WYTYCZNE
LECZENIA
HEMOFILII

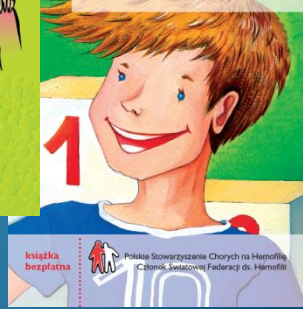
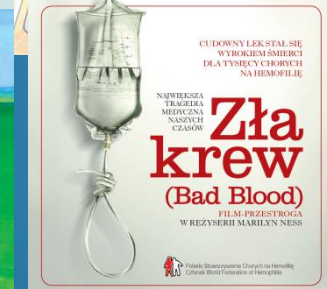
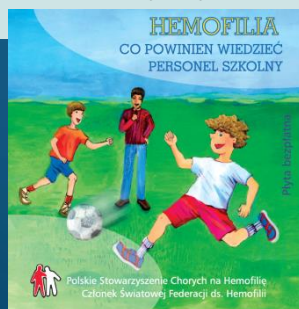
opracowane przez
World Federation of Hemophilia



Hemofilia
w wieku dojrzałym



ZAPOBIEGANIE
WYLEWOM
DOSTAWOWYM
LECZENIE PROFILAKTYCZNE
PORADNIK DLA RODZICÓW



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Sources of Polish Haemophilia Society's Finances

Any activity in the Polish Haemophilia Society is voluntary; nobody receives any financial remuneration for it. However, in order to be able to publish books and DVDs as well as to fulfill other statutory obligations we need money.

The Ministry of Health requires that we must reveal sources of our income, in particular the information whether the money comes from pharmaceutical companies. As we struggle to improve patients' care, we make efforts to base our finances on other sources than donations from pharma companies. If we do use such donations, we try to take them from various companies.

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Sources of Polish Haemophilia Society's Finances: 1 per cent from general taxation

The main source of PHS's income is 1 per cent from the general taxation (personal income tax) paid by any adult Polish citizen. When making the annual tax statement every citizen has the right to donate one per cent of the sum owed to the state to an organization of their choice provided the organization has the status of an Organization Operating in the Public Interest. PHS has had such status since 2008, which makes it possible for us to benefit from such donations.

To increase the income it is necessary to have the support of as big a number of patients and their families as possible. We have created an e-mailing group – an internet discussion group for pwh and their relatives. The group has currently about 900 members.

We have collected the e-mail addresses in hospitals, spreading the information with the help of doctors and nurses. Also our publications have been of help – each of them contains information on our Society's activity and on possible ways of supporting it. Every spring when people go through the routine of filling in their annual tax statements (the deadline being 30th April) we also take the opportunity of using our internet discussion group as a medium of spreading the information on the possibility of donating one per cent from one's tax.

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Other Sources of PHS's Income

Other sources of financing the PHS's activity are of much smaller importance. Sending hundreds of letters to the richest companies in Poland with a request for donations has brought very meagre results. This approach works almost exclusively in the case of companies employing pwh or parents of children with haemophilia.

In 2013 only 6 per cent of PHS's income came from pharmaceutical companies (that money was used mainly to organize meetings and workshops attended by haemophilia patients and doctors).

Our main source of income is 1 per cent from annual taxation, and this owes a lot to people connected with the Society and the activity of our Internet discussion group. This way of financing has proved to work quite well.

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Thank you for your attention

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