

LIFE WITH CHALLENGES

because patients deserve more



Founded in 2009

SITUATION IN R. MACEDONIA FOR PATIENTS WITH RARE DISEASES – FOCUS ON GAUCHER – ANNUAL REPORT - 2012



MAIN ACTIVITIES AND GOALS

- ❖ Helping and informing people with rare diseases, creating and sustaining communication between patients
- ❖ Raising awareness in society through education about the problems of patients with rare diseases
- ❖ Organization of public events, congresses and meetings with a goal to educate and inform
- ❖ Advocacy and lobbying for patient rights
- ❖ Support of research and education about rare diseases
- ❖ Organization of info centres for people with rare diseases
- ❖ Organization of cultural events for raising public awareness
- ❖ Distribution and printing of info-materials about rare diseases
- ❖ Social rehabilitation for people with rare diseases
- ❖ Finding funds for treatment of patients
- ❖ Documentation of patients with rare diseases

IMPORTANT ISSUES AND ACTIVITIES

- ✓ **Advocating for patients' rights ; Raising awareness in society about rare diseases, about physical and psychological consequences.**
- ✓ **Helping and informing people with rare diseases.**
- ✓ **Helping doctors to get information about diagnostics, treatment and rehabilitation of rare diseases.**
- ✓ **Communication with other organizations about rare diseases in R. Macedonia and in the world.**
- ✓ **Communication with health institutions in R. Macedonia for better treatment of people with rare diseases.**

RARE DISEASES IN R. MACEDONIA

- 10 patients with Gaucher (type 1)
- Approximately 10 patients with other rare diseases
 - ✓ Phenylketonuria (3)
 - ✓ Hereditary Tyrosinemia (1-2)
 - ✓ Mucopolysaccharidosis (2)
 - ✓ Hereditary Fructose Intolerance (1)
 - ✓ Alagille Syndrome (1-3) is not in the program for rare disease in R. Macedonia.

TREATMENT

- ❖ 2 Mucopolysacharidosis patients are treated.
- ❖ 5 Gaucher patients (type 1) are treated by Genzyme with donation with enzyme replacement therapy - Cerezyme.
- ❖ 1 Histiocytosis patient was in difficult conditions (9 month old baby), we managed to negotiate with the government so they provided finance to send the child in Germany for treatment and diagnosis, it turns out that is another rare disease and they still have trouble with diagnosis
- ❖ All the other patients today are trying to live without treatment.
- ❖ The diagnosis is on a very low level – education is needed for early diagnosis.
- ❖ Patients and parents need counseling in order to cope with the diseases.

CHALLENGES

All patients with rare diseases face psychological and physical challenges and difficulties during their life.

- **Constant pain**
- **Isolation and marginalization**
- **Difficulties in social inclusion**
- **Lack of treatment leads to reduced life span and reduced quality of life**
- **Patients are feeling different and alone**
- **Questions arise:**
 - How to talk with friends?
 - How to talk to family?
 - Is my disease real?
 - What can I do to feel better?
 - Why am I different?
 - Will I have a chance for normal life?
 - Should I tell my employers that I have a rare disease?
 - How to talk to future spouse? (boyfriend, girlfriend situations)

CHALLENGES

Families (parents) of patients with rare diseases face psychological challenges and difficulties:

- Lack of treatment leads to despair
- How to help our child (children)
- How to talk to our child?
- No answers to every day pending questions and challenges
- Why and how is my child different from other children?
- School – should I talk to the teachers?
- Should I monitor my child constantly?
- How to explain to my child about the disease
- Which doctor should we see?
- Is special care needed?
- Is psychological counseling needed?
- Do I need to behave different with my child?
- Will my child be accepted in the school environment
- Does my child have a chance for normal life?
- Are there others with such rare diseases?
- How can I fight form my child's rights to quality life?

WHAT ARE WE DOING?

- ❖ **Negotiating with the Ministry of Health**
- ❖ **Informing the President of the Government and the Minister of Finance about the importance of treatment for patients with rare diseases**
- ❖ **Raising awareness to get more support from the people in Macedonia**
- ❖ **Cooperating with the media to raise the level of awareness about our problems**
- ❖ **Cooperating with other patient organizations to act together about important patient issues**

MEDIA COOPERATION AND SUPPORT RARE DISEASE DAY 29.02.2012

Daily newspapers

❖ Dnevnik – daily newspaper

<http://www.dnevnik.com.mk/default.asp?ItemID=6A2E3A7D78373743942077317D4FDEDB>

<http://www.dnevnik.com.mk/default.asp?ItemID=099CEDCB5472FA47A4ABE965ED408DA2>

❖ Deneshen vesnik – daily newspaper

<http://www.denesen.mk/broj66/>

❖ Vecer – daily newspaper

<http://vecer.com.mk/?ItemID=CF9BD888BBEDED4AAE6F86A85D53EFA4>

❖ Focus – on line link not available

MEDIA COOPERATION AND SUPPORT

National televisions

❖ Channel 5 – news at 18.00h

<http://kanal5.com.mk/default.aspx?mId=37&egId=13&eventId=87829>

❖ Alfa TV – news at 19.00h

<http://vesti.alfa.mk/default.aspx?mId=36&egId=6&eventId=46777>

❖ News at 18.30h on Telma-

<http://telma.com.mk/index.php?task=content&cat=6>

❖ Sitel – News at 15.00h- on line link not available

❖ Sitel – morning show – 8.30h - on line link not available

❖ Alfa – portik – tv show – 10.00-12.00 h. - on line link not available

❖ Alfa – morning show - on line link not available

❖ Local television from Tetovo - on line link not available

MEDIA COOPERATION AND SUPPORT

News agency

❖ <http://mia.mk/default.aspx?mId=35&lId=1>

Internet portals

❖ <http://24vesti.com.mk/index.php/makedonija/293-makedonija/4774-2012-02-29-15-19-04>

❖

❖ <http://www.plusinfo.mk/vest/35152/Drzhavata-gi-ostavi-na-cedilo-pacientite-so-retki-bolesti>

❖

❖ <http://kurir.mk/makedonija/vesti/62626-Alarmantno-Zadeca-so-retki-bolesti-nema-pari-za-terapija>

❖

❖ <http://press24.mk/story/zdravje/%E2%80%9Ezhivot-so-predizvici%E2%80%9C-bara-terapija-za-site-pacienti-so-retki-bolesti>

❖

❖ <http://www.sky.mk/makedonija/16355.html?task=view>

CAMPAIGN - 2013

- ❖ In 2012 the association won the PAL award – Patient Advocacy Leadership from Genzyme.
- ❖ We are starting a campaign for raising public awareness about rare diseases. The campaign includes:
 - ❖ Developing a web page for information
 - ❖ Translating information about rare diseases in Macedonian language because there are no information on Macedonian language
 - ❖ Organizing press conferences and public debates
 - ❖ Rare Diseases Day – 28.02.2013
 - ❖ Cooperating with other patient associations for support in Macedonia, on the Balkan, and internationally in Europe and all over the world.

COOPERATION WITH OTHER PATIENT ORGANIZATIONS

- ❖ Life with Challenges is a member of the European Gaucher Association.
- ❖ Cooperation with the association for CML – Pepo Levi
- ❖ Cooperation with the patient association for Cystic Fibrosis – Snezana Bojcin
(both organizations have already got treatment for their patients, they are also in the group of rare diseases but they are not in the Program for Rare Diseases, but under the Health Insurance fund of Macedonia)
- ❖ The patient association in Bulgaria – Vladimir Tomov – they helped us to organize the association in Macedonia with organizing a conference in 2009 in Ohrid, Macedonia
- ❖ The patient organization in Bosnia and Herzegovina and Slovenia (we are organizing the Balkan patient meeting next year together)

NEXT STEPS

- ❖ **Research – how many patients with rare diseases are in Macedonia? What do they need? What problems do they have? What are the challenges? Are they treated somehow? What is their quality of life? Are they getting the needed hospital care? Do they have enough available information about the rare diseases?**
- ❖ **Raise public awareness on a higher level – talk about our problems and providing possible solutions.**
- ❖ **Continue communication with the Ministry of Health and the Government about resolving problem of lack of treatment.**
- ❖ **Make an effort to provide psychological counseling and support for patients and their families.**

WHAT CAN YOU DO TO HELP US?

- ❖ Share your experience in the fight for patients rights
- ❖ Help and support in education of doctors in primary, secondary and tertiary health system.
- ❖ Write support letters about the importance of treatment to our Minister of Health – Nikola Todorov, and the President of the Government – Nikola Gruevski.
- ❖ Help us provide material about how great are the benefits of diagnosing and treating the patients in early age.

HOW CAN YOU CONTACT US?

❖ [E-mail: zivotsopredizvici@gmail.com](mailto:zivotsopredizvici@gmail.com)

❖ Facebook group :

<https://www.facebook.com/groups/312483895490987/>

❖ Facebook page:

<https://www.facebook.com/LifeWithChallenge.si>

❖ Web page:

<http://challenges.think.mk/>

❖ Mob. Tel. +389 70 705 446

FINANCIAL REPORT

- ❖ Under Macedonian Laws we are not obligated as a non-profit organization to make a financial annual report if our budget is under 2500 EUR.
- ❖ Our budget last year was around 1500 EUR, and most of our activities are done with volunteers and supporters.

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THANK YOU FOR YOUR
ATTENTION

