Elena Tsoneva
Chairperson of Aniridia Bulgaria
and parent of child with WAGR syndrome

Yoana
22 years old

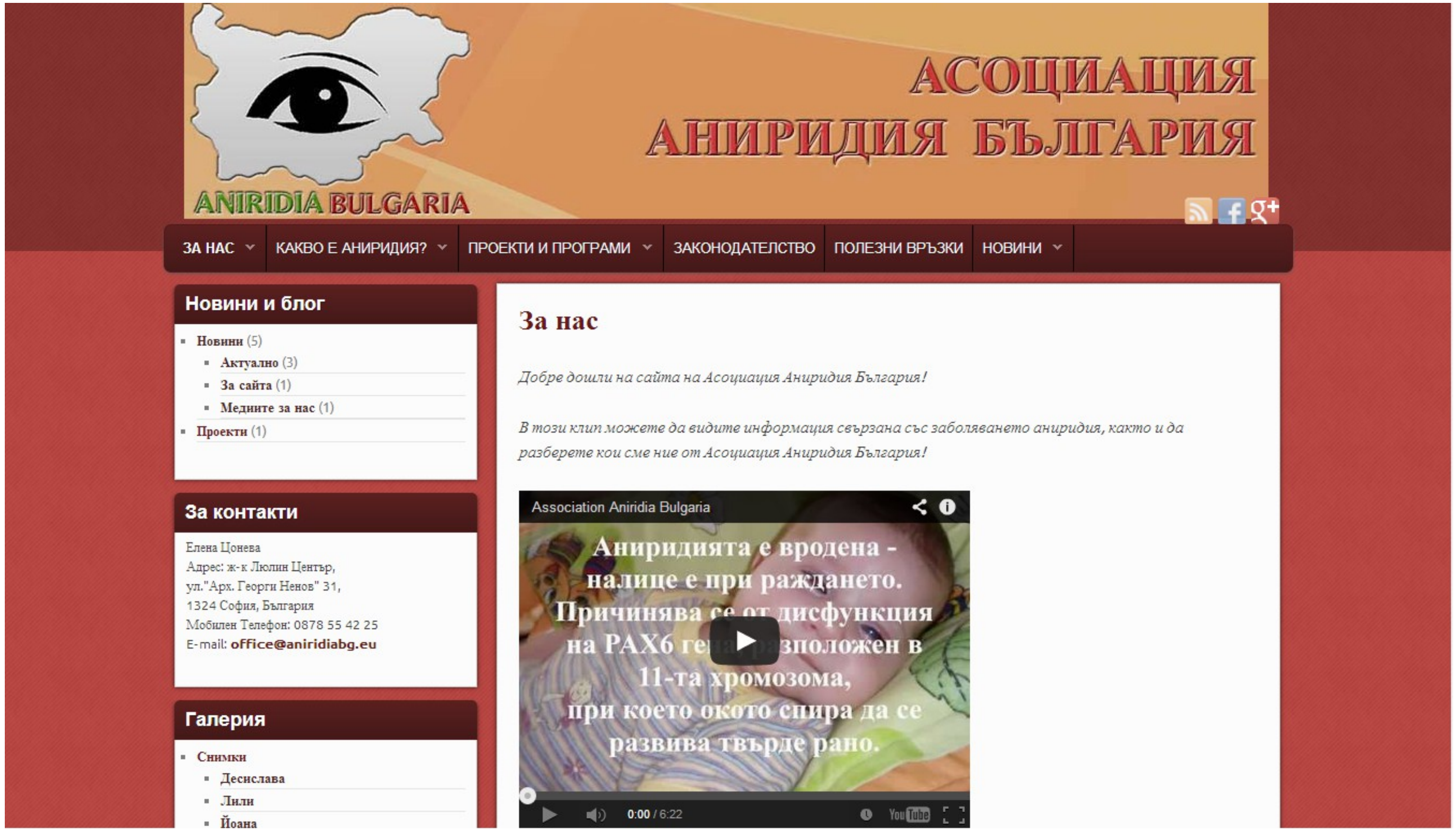
ANIRIDIA BULGARIA

Establishment

- Association Aniridia Bulgaria (AAB) was founded in 2012 as a non-government patient organisation (NGO).
- AAB is a full member of the National Alliance of People with Rare Diseases (NAPRD).
- AAB is a full member of Aniridia Europe.

Website

www.aniridiabg.eu



АСОЦИАЦИЯ
АНИРИДИЯ БЪЛГАРИЯ

Новини и блог

- **Новини** (5)
  - **Актуално** (3)
  - **За сайта** (1)
  - **Медиите за нас** (1)
- **Проекти** (1)

За контакти

Елена Цонева
Адрес: ж-к Люлин Център,
ул."Арх. Георги Ненов" 31,
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E-mail: **office@aniridiabg.eu**

Галерия

- **Снимки**
  - **Десислава**
  - **Лили**
  - **Йоана**

За нас

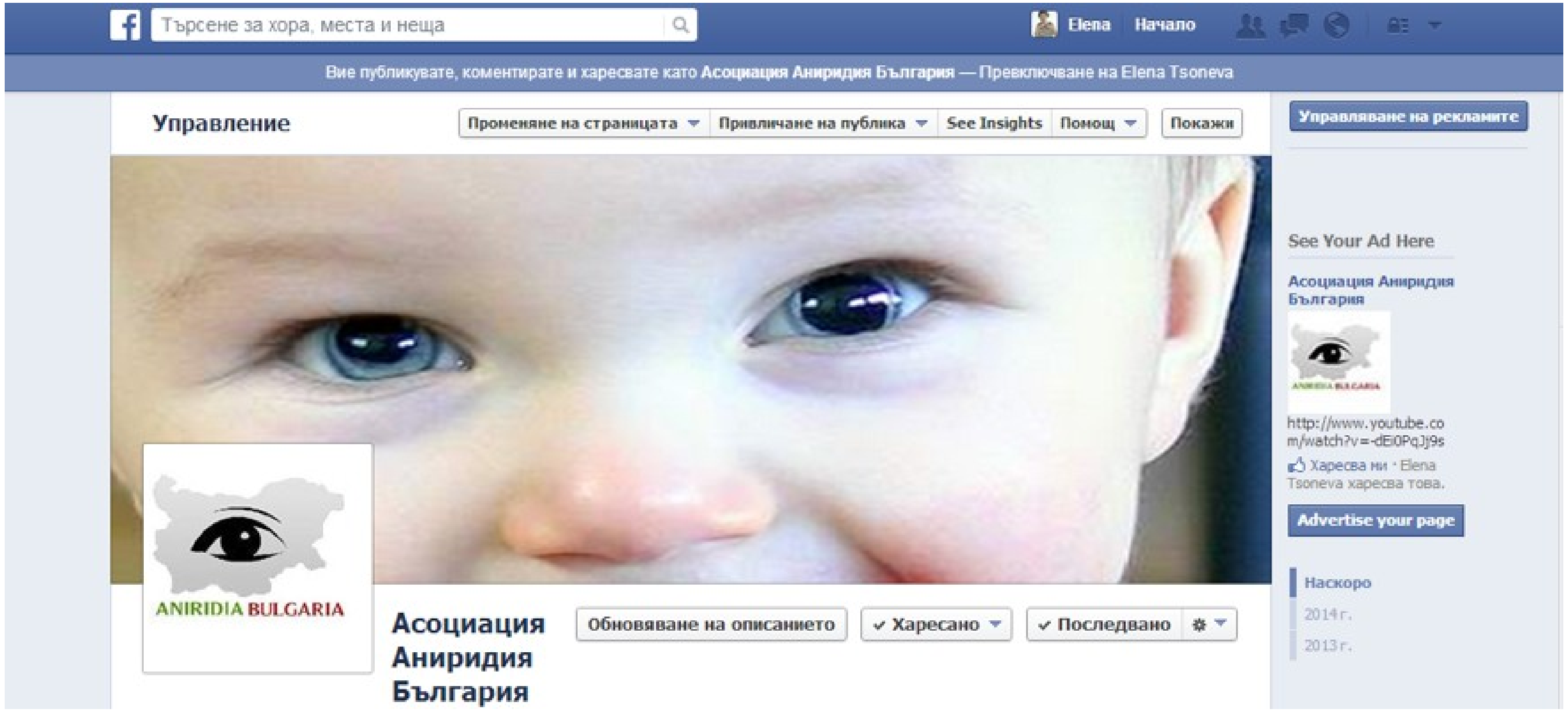
Добре дошли на сайта на Асоциация Анеридия България!

В този клип можете да видите информация свързана със заболяването анеридия, както и да разберете кои сме ние от Асоциация Анеридия България!

Аниридията е вродена -
налице е при раждането.
Причинява се от дисфункция
на PAX6 ге[illegible]зположен в
11-та хромозома,
при което окото спира да се
развива твърде рано.

We are exchanging and disseminating information about the disease.

Facebook page



Вие публикувате, коментирате и харесвате като **Асоциация Анирידия България** — Превключване на Elena Tsoneva

Асоциация Анириדия България

Асоциация Анирידия България

http://www.youtube.com/watch?v=-dEi0PqJj9s

Харесва ни · Elena Tsoneva харесва това.

https://www.facebook.com/aniridiabulgaria

Implemented Project

ASSOCIATION ANIRIDIA
BULGARIA

PROJECT :
“Building of new mechanisms
for self-help for affected people of Aniridia”

Programme to support NGOs in Bulgaria
In the EEA Financial Mechanism 2009 – 2014

- ***Project partner: Aniridia Norway***
- ***The project contained 7 basic activities***

Seminars

Seven seminars in seven different cities in the country.

Other activities

- **Develop and dissemination of information materials**
- **Providing specialised equipment and inventories**
- **Create a Registry of affected persons with Aniridia in Bulgaria.**
- **Create interactive tool for self-help**

ANIRIDIA BULGARIA

ANIRIDI NORGE

АНИРИДИЯ

ПРОФИЛАКТИКА • ДИАГНОСТИКА
ЛЕЧЕНИЕ • РЕХАБИЛИТАЦИЯ

СЕМИНАРЪТ СЕ РЕАЛИЗИРА ПО ПРОЕКТ:

Изграждане на нови
механизми за самопомощ
при засегнатите от аниридия

ICELAND
LIECHTENSTEIN
NORWAY
eea
grants

Creating new mechanisms for
self help for people affected
by the Aniridia disease

www.eeagrants.org • www.ngogrants.bg

Проектът се финансира в рамките на „Програмата за подкрепа
на НПО в България по Финансовия механизъм на Европейското
икономическо пространство 2009-2014 г.“

Current challenges

- Bulgarian legislation about rare diseases is limited, formalised, and ineffective.
- The legislation is more scientific and less practical.
- There is no judicial control over the changes in the Register of Rare Diseases at the Ministry of Health.
- **Ordinance No. 16 of July 30, 2014** the terms and conditions for registration of rare diseases and on the expert centres and reference networks for rare diseases.

Ordinance No. 16 of July 30, 2014

- Commission on Rare Diseases - Ministry of Health (MH)
- Register of Rare Diseases to MH - MH
- Centers of Expertise - National Center for Public Health and Analysis (NCPHA)
- Reference Networks - NCPHA
- Register of Centers - NCPHA
- Patient Register - NCPHA

Good practices

"My motor neurone disease is a rare disease. However, I have lived with it for 53 years and know that it is possible for people with rare diseases to live good and productive lives."

Rare Diseases

HEALTHAWARENESS.CO.UK

Stephen Hawking
"I know it's possible for people with rare diseases to live good and productive lives"

Thank you for your attention!