

# ГРОМАДСЬКА ОРГАНІЗАЦІЯ

## «ЗАХИСТ ПРАВ І ПІДТРИМКА ПАЦІЄНТІВ З АНІРИДІЄЮ ТА ВАГР-СИНДРОМОМ «АНІРИДІЯ-ВАГР-СИНДРОМ УКРАЇНА»»

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Public Organization "ANIRIDIA–WAGR-SYNDROME UKRAINE" congratulates the community of Aniridia Europe and expresses our respect:

- To all people with Aniridia, WAGR syndrome and their families;
- To all doctors treating these patients;
- To all researchers trying to find ways to overcome such illnesses as Aniridia, WAGR-syndrome and related diseases;
- To all sponsors, benefactors and just good friends.

Our Public Organization "ANIRIDIA–WAGR-SYNDROME UKRAINE" unites people with Aniridia and WAGR-syndrome in Ukraine. So far, our organization has managed to find 59 patients with Aniridia, among them 44 children under the age of 18, including 5 children diagnosed with WAGR syndrome.

On May 8, 2023, our organization was 5 years old.

5 years on the global scale is not many but for our Ukrainian organization, this is a big step towards the future. We hope that the happy future of our organization is ahead and we will be able to bring more benefits to society.

We are proud to be independent and free. We ask the European Aniridia Society not to consider our organization as a part of the organization from unfriendly neighboring country Russia. The Russian Federation is leading an unjustified and vile war against our native Ukraine. Our organization has no moral right to have any contacts with representatives of the aggressor country which is killing the civilian population, destroying entire cities and occupying the sovereign territories of Ukraine.

During the last year the Ukrainian patients with Aniridia and WAGR syndrome were forced to save their lives in the basements or leave their native homes. Some members of our organization have lost possibilities to have any medical care. Unfortunately, the contacts with some families were lost.

But, despite of all the difficulties, we support each other, communicate and look for new useful contacts.

In particular, we have recently taken part in all events held by international Aniridia organizations, such as:

- "Aniridia Day - 2023" - June 21;
- "Rare Disease Day 2023" - February 28;
- "WAGR Awareness Day 2023" - November 13.

Over the years of our activity, we have found some friends and sponsors. Even during the war every person with Aniridia can receive up to two photochromic prescription glasses per year for free from our sincere friends.

Unfortunately, as a result of Russian aggression, our patients do not have the opportunity to have a full-fledged ophthalmological and genetic examination and examinations by specialists of

other related diseases in a timely manner. It is a health hazard and also life threatening for our members, that we are extremely concerned about.

ANIRIDIA–WAGR-SYNDROME UKRAINE makes every effort to be useful to adults and children with Aniridia. We do everything so that Ukrainians and Ukrainian doctors know about Aniridia and related problems.

We give hope and confidence to families that they are not alone with this disease, we provide psychological support.

The aim of our organization is to help Ukrainian people with Aniridia and their families to be happy, healthy and to have the most comfortable, bright and colourful life!

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Best regards,

President of the Public Organization

«ANIRIDIA–WAGR-SYNDROME UKRAINE». Mykola Snurnikov