AGO
ALLIANCE
POLAND

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SMALL STEPS, BIG HELP

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Educational material for the "Youth for Rare Diseases" competition

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Understand. Support. Change.

Understand rare diseases, support families and research, and together we will turn invisibility into hope.

Action. Generation. ResponsibIlity. – for Rare Diseases

The aim of the campaign is to engage the young generation in activities promoting awareness, research, and support for people with rare diseases.

#MISJAAGO

AGO Alliance Poland Foundation

It is a non-profit organization run jointly by patients and scientists, born out of love, determination, and the urgent need to develop treatments and help children with the rare disease
- AGO syndrome.

INTRODUCTION – WHY ALL THIS?

Helping doesn't have to be difficult or expensive.

All it takes is an idea, the commitment of a few people, and the desire to change the world.

In Poland, there are approximately 3 million people living with rare diseases – children, adolescents, and adults who often wait for diagnosis, treatment, or simply understanding. One of these groups are children with AGO syndrome, including my son Albert.

The only hope for children with AGO syndrome is to create a drug specifically for them. To begin development, we need **PLN 1,000,000** for research.

Children with AGO syndrome, like many others living with rare diseases, need not only medicines but, above all, allies – people who will share their stories and help scientists reach the goal.

Schools, students, and teachers can play exactly that role.

THIS BOOKLET IS AN INSTRUCTION

Step by step, I'll show you how to organize a fundraising event at your school to help with AGO syndrome—from concept to promotion.

You can do it in a month.

**YOU DON'T NEED A BIG BUDGET.
JUST A BIG HEART.**

WHAT IS CROWDFUNDING AND HOW DOES IT WORK?

Crowdfunding is a way for many people to come together to finance a single cause. Instead of one large donation, hundreds of small contributions can be made, adding up to real help.

TYPES OF CROWDFUNDING

DONATED
you donate out of good will, without rewards

AWARDED
you receive a thank you note, a card, a gadget

SOCIAL
charity collections – e.g. for treatment, research, equipment, educational activities

IT IS A DEMOCRATIC AND MODERN TOOL – IT CONNECTS PEOPLE, EMOTIONS AND TECHNOLOGIES.

HOW CAN THE SCHOOL PARTICIPATE IN THIS?

- by organizing an online fundrising (e.g. on Zrzutka.pl or Siepomaga.pl)
- creating a mini event, the proceeds of which go to a specific cause
- engaging the local community – parents, neighbors, students, media

CROWDFUNDING ISN'T JUST ABOUT MONEY. IT'S ABOUT A COMMUNITY THAT BELIEVES THAT SMALL STEPS CAN CHANGE THE WORLD.

HOW TO ORGANIZE A CAMPAIGN – FROM IDEA TO SUCCESS

STEP 1: CHOOSE A GOAL

Consider what exactly you are raising funds for – e.g., supporting research on AGO syndrome, purchasing rehabilitation equipment, organizing a school “Rare Disease Awareness Week.”

STEP 2: ASSEMBLE A TEAM

Every action requires people with different talents.
Divide the roles:

- Project Leader – coordinates the entire project
- Promotion and Media – graphics, posts, stories
- Finances and Contact – with the foundation and school
- Creatives – ideas for events, videos, slogans

STEP 3: PLAN YOUR BUDGET AND SCHEDULE

- Select event dates and tasks for each person.
- Determine how much you want to raise and by when.
- Determine how you will measure progress (e.g., weekly reports).

Planning tools:

- Google Sheets (table with tasks and dates)
- Trello / Asana (to-do list)
- Notion (communication plan and visual calendar)

STEP 4: PREPARE MATERIALS

Take photos, videos, and write descriptions. You don't need professional equipment – just a phone and an idea.

What you can record:
students talking about the campaign
teacher or parent commentary
video with the slogan: "Your energy, their hope!"

Use free tools:

- Canva (posters, posts, flyers),
- CapCut / InShot (short videos),
- Google Slides (presenting results)

STEP 5: PROMOTE THE CAMPAIGN

Spread the word about the campaign before, during, and after it begins.
The biggest mistake is silence.

Use these channels for promotion: Instagram and Facebook, the school newspaper, the radio station, and local websites and newspapers.

How to write posts: short (up to 5 sentences), emotional, with an image or video,
with a hashtag and link.

Hashtags:
#misjaAGO #OdkrywamyLek

STEP 6: INFORM AND THANK

THANK YOU!

Every donation shows trust.
Show the results, count the funds raised, and post thank-yous.

Update sample:
"Thanks to you, we've already raised 70% of our goal! Your cookies, concerts, and posts are truly changing the world. We only have 5 days left to surpass 100%!"

TOOLS AND TECHNOLOGIES

ORGANIZATION TOOLS

GOOGLE DRIVE
files and forms

TRELLO
action plan

CANVA
graphics

CAPCUT
video editing

OBS/STREAMYARD
live broadcasts

GOOGLE MEET/ZOOM
organizational meetings

PROMOTIONAL TOOLS

INSTAGRAM
reels i stories

TIKTOK
short behind-the-scenes videos

FACEBOOK
events
and longer posts

YOUTUBE
videos
and summaries

START SUPPORTING

- Join our fundraiser at SIEPOMAGA.pl
- Make a donation
- Set up a fundraiser for your team
- Start fundraising

COMMUNICATION

- Contact the foundation: konkurs@agoresearch.org
- Set up an email address for the project, e.g. *male.kroki@szkola.pl*

HOW TO TALK ABOUT RARE DISEASES

RULES OF COMMUNICATION

1. Start with the person's story, not the definition of the disease.
2. Speak the language of hope, not pity.
3. Use simple comparisons.
4. Always demonstrate the meaning and value of research.

EXAMPLE SENTENCES

1. "Rare diseases are laboratories of hope – thanks to them, science moves forward."
2. "Rare diseases aren't as rare as we think. Everyone knows someone affected."
3. "For us, it's a campaign; for them, it's a chance for a cure."

ONLINE AND MEDIA PROMOTION

HONESTY IS THE EASIEST WAY TO GET PEOPLE TO TRUST YOU.

TELL THE TRUTH – DON'T EMBELLISH HISTORY

ALWAYS CITE SOURCES OF INFORMATION

TAKE CARE OF THE PRIVACY OF PEOPLE WITH DISEASE

GIVE THANKS – ANY HELP IS APPRECIATED.

POST WISELY

- short, emotional texts,
- photos from preparations,
- quotes from students and teachers.

SHOW THE PROCESS, NOT JUST THE RESULT

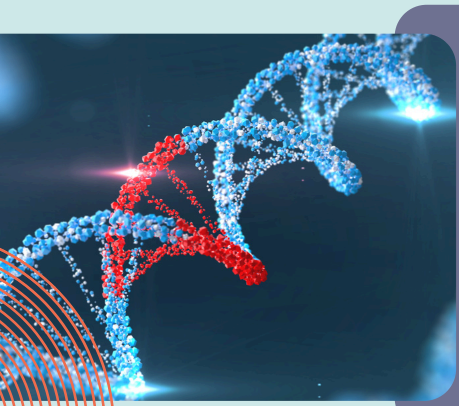
- Preparations, rehearsals, baking, posters.
- People love to see what happens "behind the scenes."

TAGLINES AND CTAS

- “Join us – every gesture is a sign of hope.”
- “See how students have done something great!”
- “Help us raise funds for research.”

HOW TO TALK ABOUT AGO SYNDROME

Children with AGO syndrome develop more slowly, often learning to speak or walk later, but they retain a profound curiosity about the world and a zest for life.
There is no cure yet, but research is ongoing.
The goal is to understand how to "repair" this delicate mechanism in cells.



AGO syndrome is an ultra-rare genetic disorder, discovered only a few years ago.
It is caused by mutations in the AGO1 or AGO2 genes, which are responsible for the proper functioning of our cells.
You could say that these genes are the conductors – they direct the orchestra of genetic information.
When the conductor makes a mistake, the orchestra continues to play – just in a different way.

HOW TO TALK ABOUT IT

Speak simply and empathetically:

- instead of "sick children" → "children with a rare disease,"
- instead of "suffering" → "living with the disease,"
- instead of "fighting their fate" → "looking for a solution."

Avoid pity — speak about strength, science, and collaboration.
Emphasize that research on rare diseases helps not only a few, but all of medicine — because it leads to new gene therapies and a better understanding of human DNA.

EXAMPLE OF A STATEMENT DURING A MEETING

We help children with AGO syndrome – an ultra-rare genetic disorder.
By supporting research, we give scientists the tools to find a solution.
Every donation is a real step towards hope.

HASHTAGS TO PROMOTE THE CAMPAIGN

#misjaAGO
#OdkrywamyLek

EXAMPLE

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HOW TO ORGANIZE SCHOOL EVENTS

FAIR AT SCHOOL OR ONLINE

- Students display their handicrafts, photos, graphics, books, and preserves at school or on the school's social media profile.
- The person who selected the product makes a donation to the team's fundraiser box on Siepomaga.pl.

TALENT SHOW IN SCHOOL OR ONLINE

- Organize student performances – a concert, poetry reading, or talent show broadcast on YouTube, Instagram, or Facebook.
- Add a link to a fundraiser – viewers can donate to rare disease research.
- Combine art with charity – hold an auction, for example, "Bid for a song dedicated to you."

EXHIBITION OF WORKS "INVISIBLE DISEASES"

- Topic: "Invisible Diseases – Visible Power."
- Accept artwork, photos, collages, and poems in person or online.
- Add a QR code to the fundraiser and descriptions:

“This work is inspired by the story of children with AGO syndrome.”

#MISJAAGO CHALLENGE

- Each student nominates three people to complete a simple challenge (e.g., 10 push-ups, painting a heart, recording a short video about empathy) and donates a symbolic amount (e.g., PLN 5–10) to the fundraiser.

SCHOOL PODCAST "VOICE OF HOPE"

- Team: 2 presenters + 1 editor + 1 promoter
- Apps: Anchor, Audacity, GarageBand
- Topic: "How has helping changed our school?"
- Publication: Spotify, YouTube, school website

RARE DISEASE AWARENESS WEEK "SCIENCE AND HOPE"

- 5 days: Genes / Empathy / Science / Community / Hope
- Daily quiz, film, presentation, conversation
- Friday – turquoise finale
- Photo show and presentation of the diploma of the school in solidarity with people with rare diseases.

Your energy, their hope – get your school moving!

SUMMARY

- Every initiative begins with a conversation, a single idea.
- You don't have to change the world alone – you just need to inspire others.
- By helping, you learn to organize, speak, act, and collaborate.
- It's a lesson that will stay with you for a long time.

CONTACT

- AGO Alliance Poland Foundation
- www.agoresearch.org
- konkurs@agoresearch.org
- contact@agoresearch.org

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