



Member organizations of OIFE

OIFE
Schotelveldstraat 17
2801 Heffen,
Belgium

Oslo, 6. Juli 2021

Help us make a big IMPACT!

Dear member organizations of OIFE.

As you probably know the IMPACT survey was launched in English language version this week and on Thursday the 8th of July seven more language versions will be added: Italian, Russian, Dutch, German, French, Portugese and Spanish: www.impactsurveyoi.com

This is your project as well and we need your help!

We would like to stress that the IMPACT survey is not a project of the OIFE and the OI Foundation only. It's a project for **all OI-organizations worldwide** and for the entire **global OI-community**. It's therefore essential that you as OI-organizations help us to spread awareness about the IMPACT survey to recruit as many participants as possible. **Without your help, we will not be able to reach enough participants.**

You can get national reports for your organization!

If your country gets **more than 20 individual replies** to the survey, you can request a national report with statistics from your country after the project is finished. You can use this data in your national policy work, when speaking to bureaucrats, politicians, or media about the need for improvement of services to people with OI.

What can you do to help?

Most of our member organizations are run by volunteers, who we know have limited time and resources to get involved in projects like this. We therefore understand that everyone cannot do everything. But we have made a list of suggestions of **things you and your organization CAN do**. These are **only suggestions and no requirements!** Feel free to promote the survey in other ways, if you think that will be more efficient.

Registration number Chamber of Commerce (KVK)
Eindhoven/NL: V40240387
ANBI – NL – non-profit organisation
Fiscal number 8028 90 891

SWIFT / BIC: BYLADEM1ANS
IBAN: DE 84 7655 0000 0000 6123 09
Sparkasse Ansbach, Postfach 18 52,
D-91509 Ansbach, Germany



- **Get personally involved!**
 - Take the survey yourself if you are in the target group!
 - Help others who are interested, but who need help with content or language
 - Encourage Board members/front figures in your organization to take the survey and post about it

- **Inform your members directly in writing**
 - Via individual email
 - Via newsletters or email newsletters
 - Via old fashioned letters (snail mail)

- **Inform your members about the survey in a meeting/event**
 - Speak about the survey in face to face events and/or distribute the flyer
 - Speak about the survey in online events – *please let us know if you want OIFE's help or presence to present something!*

- **Include information on your webpage**
 - Include a page about the survey on your webpage
 - Include a news post about the survey on your webpage

- **Create buzz in Social Media**
 - Use the banner (see OIFE's FB-page as example)
 - Share and like OIFE's posts on social media
 - Publish posts in your own language about the IMPACT survey
 - Share the animated video
 - Create your own videos with people from your organization encouraging people to take part!
 - Use the hashtag #IMPACTsurveyOI
 - Use the Facebook-frame "I made an Impact!" – *coming soon!*

- **Encourage OI-professionals or healthcare providers to help!**
 - Encourage OI-clinicians (or researchers) who see a lot of people with OI to spread information and encourage people with OI & parents to take part.
 - Encourage hospitals/centers of expertise to distribute the flyer

Can we have costs covered?

If you have costs connected to printing or postage, OIFE can consider helping your organization with covering some of these costs. Please reach out to us with a request incl. a budget before counting on our support!

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Key messages!

Make sure to check that the information you give is correct when promoting the survey.

Here are some key messages, that can be good to remember:

- It's **more than a survey** (we know most people hate surveys)
- It's a global research project of **high scientific quality and value**, with central OI-professionals from US, Canada and Europe involved.
- Lack of big data is a big problem in rare conditions – this is our way of dealing with it
- Data will be used to enable **better diagnosis, treatment and care**, and to support availability of potential **future treatments** for OI.
- Survey & communication material is available in **eight languages** (English, Spanish, German, French, Dutch, Italian, Portuguese and Russian)
- It's a unique opportunity to provide documentation from the perspective of people with OI (nothing about us without us)
- It's the first **global** research project on OI ever
- The **patient organizations** (OIFE & OIF) will be in **charge of the data** after the project!
- The survey is anonymous, and privacy is well taken care of
- The survey will be **open until September 10th 2021**

Where can I find tools to help me?

We recommend the following sources of information:

1. OIFE's resource page on IMPACT: www.oife.org/impact (auto translation available)
2. The IMPACT survey page itself: www.impactsurveyoi.com
3. The Communication package from Wickenstones [available via Dropbox](#) which include 8 language versions of:
 - a. A flyer which can be printed or distributed by email
 - b. A powerpoint with suggestions for text you can use in emails or social media
 - c. The video files for the animation video + screenshots from the video – also available on YouTube: <https://www.youtube.com/watch?v=ulNeWu4KzFo>

Good luck and have a nice summer!

Kind regards on behalf of OIFE's Executive Committee

Ingunn Westerheim
OIFE President

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