Official pre-launch of THE iMPACT SURVEY

A collaboration between the OIFE, the OI Foundation & Mereo Biopharma
What is the Impact survey?

«Living with Osteogenesis Imperfecta: understanding experiences based on Community Insight & evidence»

• Collaboration between organizations, OI-experts and industry
• One time survey – NOT a registry/database
• Purpose is to gather documentation & evidence about the impact of OI on people and the national healthcare systems
• A scientifically validated and published international set of data will be used:
  • in national health technology assessment & reimbursement discussions
  • to improve treatment & services
  • in advocacy work (nationally and internationally)
• After articles & reports are written OIFE, OIF & Dr Frank Rauch will manage the data, which can be reused for
  • Other esearch projects
  • Processes connected to other medicines & advanced treatments (ex: stem cells and gene therapy)
Steering Committee

Chairman Dr Frank Rauch

Katherine Bache OIF
Tracy Hart OIF

Dr Cathleen Raggio
Dr Michael Bober

Ingunn Westerheim OIFE
Taco van Welzenis OIFE

Dr Oliver Semler
Dr Lena Lande Wekre

Wickenstones (external company)

Jessica Riviere Ultragenyx
James Clancy Mereo
Arun Mistry Mereo
Claudine Woo Ultragenyx
What do we need to know in this project?

Patient journey

• Understand the **Patient Journey** better:
  • Which professionals do you see?
  • How often do you see your GP?
  • Do you have access to specialists/centres of expertise?
  • Do you have regular follow-ups?
  • Do you have access to genetic testing?
  • Which treatments are available in your country?

• Are people with OI big consumers of healthcare or not?
• Do people in X & Y country have access to treatment & services they need?
What do we need to know in this project?

Impact of OI on QoL

- What does OI mean for children and adults beyond fractures?
  - How does it affect Quality of Life?
    - Fractures?
    - Breathing, blood pressure, hearing?
    - Pain & fatigue?
    - Anxiety or worries?

- Example:
  - if a treatment does not reduce fractures, but significantly reduces pain and fatigue, it’s important to have data on pain and fatigue

Medium knowledge gaps
What do we need to know in this project?

**Economic impact**

- What is the economic impact of OI on people with OI, caregivers and families?
  - Direct healthcare related costs (such as hospital visits, surgery, medication, medical equipment like rods etc)
  - Indirect costs (such as mobility aids, adaptations, assistance, loss of income, family costs etc)
  - And who pays for it? Are the expenses covered?

- **Why do we need to know** about costs?
  - Because the authorities approving drugs care about cost/benefit when new treatments are up for approval.
  - Which costs can the larger society save if you get X% better from this medication?
Just another survey...?

...or a research project that will benefit all parties?

...or a unique opportunity!

THE IMPACT SURVEY

A collaboration between

PEOPLE WITH OI & PARENTS

CLINICIANS & RESEARCHERS

INDUSTRY

OI-GROUPS

BIG DATA

GLOBAL
WE NEED YOUR HELP!

IT IS NOT ENOUGH THAT THE ORGANIZATIONS ARE AWARE AND FEEL OWNERSHIP -

INDIVIDUAL MEMBERS & THE OI-COMMUNITY NEED TO BE AWARE AND BE MOTIVATED.

PROFESSIONALS NEED TO KNOW AND SUPPORT!

AND ALL PARTIES NEEDS TO KNOW WHAT’S IN IT FOR THEM!
Clinicians, researchers & companies - what’s in it for them?

Big data and more knowledge about OI from the patient perspective, which can be used to improve clinical work, be used in future research projects and hopefully provide easier access to new medicines.
What’s in it for us? The OI-organizations

Data we can use when advocating for better services like expert centers or adult clinics.

Data we can use if NFOI is asked to contribute in national processes to approve new medicines.
What’s in it for us? Parents & people with OI

Data that can be used to find a cure for OI?

More knowledge about OI – which leads to better treatment

Access to more efficient medicines which reduce pain and fractures
Living with osteogenesis imperfecta: understanding experiences based on community insight & evidence

COMMUNICATIONS TOOLKIT IN 8 DIFFERENT LANGUAGES:

English, Spanish, Dutch, Italian, Russian, Portugese, German and French

#impactsurveyOI
Thank you for being part of The iMPACT Survey!

This toolkit contains core materials to help you to raise awareness, explain the purpose of the survey, and encourage participation.

This toolkit provides support on:

**WHEN?**

The timing of communications

**HOW?**

Channels of communications

**WHAT?**

Content of communications

Please feel free to use the contents of the kit in addition to your own photos and materials.

Download communication package on OIFE’s resource page: www.oife.org/impact
Introducing The IMPACT Survey...

IMPACT is an international survey on the socioeconomic impact of OI on people's lives, their families and the healthcare system.

IMPACT launches at the end of June 2021 and will be running until 10th September 2021.

IMPACT is for people with OI, and parents/caregivers of children with OI.

Have an impact on the future of OI by completing the survey at www.impactsurveyoi.com and spreading the word.

#impactsurveyOI
Contents
Included in the toolkit...

- Landing page orientation
  - An annotated screenshot of The IMPACT Survey landing page

- Rollout plan, roadmap and timings
  - Guidance on the scheduling of announcements and activities in support of The IMPACT Survey

- Short animation
  - A short visual clip to use on social media posts, presentations and other communications

- Campaign flyer
  - A 1-page pdf document describing the purpose of The IMPACT Survey with links to the survey itself once it goes live

- Email content
  - Suggested content to introduce The IMPACT Survey and support the flyer

- Social media messaging
  - Suggested messaging and content for social media channels

- Speaker slides
  - IMPACT Survey information and templates for potential use in oral presentations

#impactsurveyOI
Survey landing page

Until the survey launches, a ‘pre-launch’ page will remain live and signpost people to further information.

How it will look after launch June 30th

visit impactsurveyoi.com

To start the survey, please select a language

The IMPACT Survey is a joint project between the patient organizations Osteogenesis Imperfecta Federation Europe (OIFE) and the Osteogenesis Imperfecta Foundation (OIF), supported by Myego BioPharma.
How it will look after launch June 30th II
After you took the survey - tell your friends!
Campaign flyer

What this is
The campaign flyer contains all the basic information about The IMPACT Survey and links/a QR code leading to the landing page.

How and when to use it
Please attach the campaign flyer to emails and feel free to print it out and distribute paper copies.

Where to find it
The campaign flyer was included as an email attachment along with this toolkit.
Dear [reader/member/friend],

We’re excited to share news with you of the upcoming IMPACT Survey, an international survey aimed at capturing and quantifying the real impact OI has on people’s lives to enable better diagnosis, treatment and care, and to support availability of potential future treatments for OI.

The IMPACT Survey launches at the end of June 2021 and will run until 10th September 2021.

If you have OI, or are a parent/caregiver of a child with OI we want to hear from you. Please share the attached flyer with your friends and family and find out more at: www.impactsurveyoi.com

Get involved and have an impact on the future of OI by spreading the word and having your say!

The IMPACT Survey is live – get involved and have your say!

Dear [reader/member/friend]

We’re delighted to announce that The IMPACT Survey is now live and will be running until 10th September 2021.

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The IMPACT Survey is closing soon – get involved and have your say!

Dear [reader/member/friend]

The IMPACT Survey has been running for [X weeks] and remains open until 10th September 2021 – don’t miss the opportunity to share your experiences and get your voice heard.

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[insert animation]
Roadmap and timings

Timing of suggested activities

**PRE-LAUNCH**
OIFE AGM 2021

- Email shot from OIF to their members
- Email shot from OIFE to OIFE member organizations -> individual members
- Social media posts

**LAUNCH**
END JUNE 2021

- Email shot to OIFE/OIF members with campaign flyer – it is OPEN
- Email to professional organisations with campaign flyer – it is OPEN
- OIFE Magazine 2-2021
- Social media posts

**POST-LAUNCH**
OIF VIRTUAL CONFERENCE – MID JULY

- Email shot to OIFE/OIF members with flyer
- Email to professional organisations with campaign flyer
- Social media posts
- Social media posts
- Announcement at OIF Virtual Conference (July 11-12th)
Launch nr. 2 will take place at OIF Conference 2021 – also in Spanish & French!

www.oif.org/virtualconference
ANY QUESTIONS?

#impactsurveyOI