



### 14th PID Forum

COVID-19 & PANDEMICS MANAGEMENT:
PROTECTING THE MOST VULNERABLE

September 30, 2020, 15:00-16:30

Virtual Forum
Hosted by:
MEP Tomislav Sokol
(EPP, Croatia)



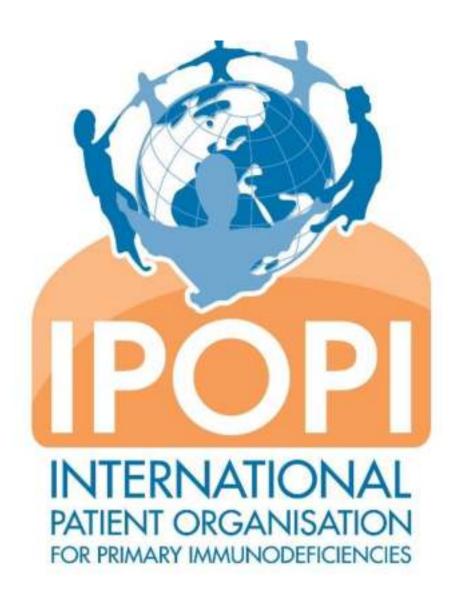




COVID-19 & PANDEMICS MANAGEMENT:
PROTECTING THE MOST VULNERABLE
30 September 2020
15:00 – 16:30

# Setting the Scene

 Martine Pergent, President of the International Patient Organisation for Primary Immunodeficiencies (IPOPI)



IPOPI 14<sup>TH</sup> EUROPEAN PID FORUM

**COVID-19 & Pandemics** 

Management:

**Protecting the Most** 

**Vulnerable** 

September 2020

# IPOPI cooperative work on COVID-19



### As an introduction

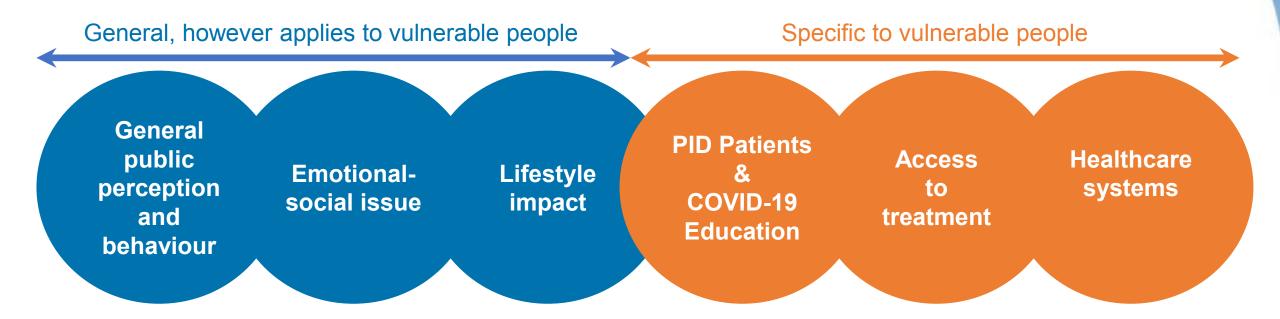
- Covid-19 highlights problems that already existed for long
- The pandemic: an eye opener for general public:
  - How is life with a compromised immune system

And also on « old » medicines ...

- Plasma
- Immunoglobulins



## We have identified 6 key issues





# What helps people with rare conditions is often helpful for all!

General public perception and behaviour

Not aware that there are vulnerable people like people with rare conditions

General prevention guidelines are not

**Emotional**social issue

Patient feel more isolated than ever.

Mental health not taken into account Lifestyle impact

Information do not always in everyday life

What is true, what is fake news?



harmonised

# Specific issues and some examples of focus areas

PID Patients & COVID-19 Education

Schools, companies are not aware of, or don't understand vulnerable people

Difficult for a COVID-19 team to reach out the the patients specialist for advice including international specialists (rare diseases) Access to treatment

Treatment breakdowns, tension on medicines (lgs)

Too much paperwork and nobody to deal with this during shut down

Healthcare systems

No/few specific protocols or procedures for rare diseases

Still no or sudden possibility for home therapy

# The pandemic challenges a diverse and complexe Stakeholders' ecosystem



# What we would love to hear from the different stakeholders?

#### Information on COVID-19

- Concrete, put into context, useful information, ...
- Harmonised informations

#### Information on rare diseases specificities:

 What they imply for the general public's behaviour, HCPs' organisation

#### Communication

- Campaigning on daily best practices
- Fight fake news and activists

#### Access to hospitals and specialists

Adapt access to treatment and monitoring

#### Cooperation

- · Research on the virus itself
- Multidisciplinary ways for working and organising, promoting holistic approaches
- Encourage cross boarder harmonized approaches (information sharing, clinics and research, data collection, ...)

#### Innovation

- Develop new ways for organising (diagnosis, treatment, following up, including home treatment)
- Promote use of new technologies (AI, e-medicine)

#### Human rights

Promote health coverage for chronic diseases in every country



### Last but not least: Access to treatment

### Facing the decline of plasma donations

- >Ensure patients can continue to access their IG therapy in an optimal manner
- Especially those with no alternative medicine such as PID patients

#### >Need to:

- Insure an open and transparent dialogue with all stakeholders
- Insure that appropriate action can be taken anticipatively, including demand management plan to allow prioritisation in case of tension.



# Thank you for your attention!



#### Thank you to the

#### **IPOPI Learning Expedition team**

- Natalie Helena-Andrews (IPOPI, Portugal)
- Roberta Anido de Pena (Argentina)
- Sian van den Bogaerdt (The Netherlands)
- Carolyn Dews (Australia)
- Magdalena Doragrip (Sweden)
- Christine Jeffery (Australia, IPOPI)
- Igor Koruga (Serbia)
- Julia Nordin (Sweden, IPOPI)
- Vida Ramsak (Slovenia)
- Megan Ryan (USA)
- Kristina Skeries (Canada)
- Leire Solis-Garate
- (IPOPI, Spain)
- Dimas Sugiharto (Indonesia)





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# The role of patient organisations during pandemics: discussion with national patient groups

- Birgit Schlennert, Deutsche Selbsthilfe Angeborene Immundefekte e.V. (DSAI) (Germany)
- Izabela Morawska, Immunoprotect (Poland)
- Savvas Savva, Cyprus Primary Association and Friends (Cyprus)
- Anneli Larsson, Primaer Immunbrist Organisationen (Sweden)

# dsai e.V. German Patient Organisation for Primary Immunodeficiencies

# **Challenges and Chances during Corona Pandemic**

IPOPI 14th PID Forum September 30, 2020

#### **Overview Germany**

- January 27: first case
- mid of March: succesive closure of schools, kindergardens in all German states
- March 22: nationwide contact and exit restrictions
- now: restrictions + rules (masks) still in place
  - vary from state to state and week by week
- schools open again with temporarily closures
- cases by Sept. 25: 280.223

deaths: 9.443

#### **Challenge: patients worried with lots of questions**

- significant increase of requests, especially at the beginning of the pandemic
  - > first: mostly medical questions
  - > then: also legal, labor law, social law
- no reliable information available
- guideline from German Society for Intensive and Emergency Care
  - > triage: low priority for intensive care beds for patients with "severe and irreversible immunodeficiency"

#### **Solution approach:**

- good general guidelines from Robert Koch Institut for Sars Cov2 infection prevention and hygiene measures
- direct approach to PID-doctors and medical societies for reliable statements
   guidline from PID working group API
- sub-area "Corona" on dsai-Website
   collection of reliable links and data (IPOPI, medical societies etc.)
- virtual Q&A round with a professor
- establish contacts between patients
   similar circumstances, extremly worried vs. optimistic

#### Still challenging:

- no medically or legally binding guidline, if PID-patients belong to "risk group"
- · problem of triage still unsolved
- each patient must discuss individualized "Corona-approach" with his/her doctor
- for dsai-team: stay updated to have appropriate advisory skills

#### **Challenge: long term perspective for patients**

- during first weeks: sick leave often possible, employers sympathetic,
   self-isolation possible or mandatory
- now: resumption of work, back to school
   understanding for situation of PID patients decreases
- existential fear, economic problems
- not only patients facing the problems but also relatives
- psychological problemes begin to increase

#### **Solution approach:**

- letter to ministries of culture (responsible for school)
- letter to ministries of health

#### still challenging:

- health and education organized decentralized > no consistant rules
- home office not possible for many jobs
- home-schooling often not possible

#### Challenge: availability and effectivness of treatment

- iv-therapy not possible doctor's offices closed, hospitals focused on preparation for COVID19
- general fear of shortage of plasma/immunoglobulins
- treatment in the future
   vaccination, SARS-Cov2 antibodies

#### **Solution approach:**

- unavailability of doctors only short term
- switch from iv-therapy to sc-therapy
- broad awareness campaigns for plasma donation in Germany
- positive aspects: words like immunity, plasma, antibodies now more common in general public > chance to raise awareness





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# 14th PID forum – the role of patient organisations during pandemics.

Izabela Morawska, Poland
Association for Patients with Primary Immunodeficiencies "IMMUNOPROTECT"
30th September 2020

# The less we know the more afraid we are... First days of COVID-19 pandemics

- Fear of unknown
- Disinformation
- Lack of clear goverment guidelines
- Solution....









- Guidelines **12 principles of protection against coronavirus**
- "How to wear masks" graphics
- Translation of IPOPI/ESID statements
- Cooperation with doctors: prof. Sylwia Kołtan, lek. Ewa Stawiarska
- Webinar patients were able to ask questions to the doctor, nurse and representative of our association



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# How to wear face masks









# Going viral

## Psychological issues of lockdown

Stress and fear caused by the pandemic

Lot of people contacted us because they needed someone to support them

Solution: we have introduced a psychologist on-call free of chargé to all of the patients in need



## Future of IgG treatment?

- Patients were concerned about the future of immunoglobulin treatment
- Solution: we have published informations based on special government regulations including the possibility of receiving the drugs for 6 months, collecting them from a hospital pharmacy by an authorized person or home delivery of medicines
- We are constantly monitoring availability of the treatment



### World PI week

- We have focused on the "I count on you" campaign and on the publication of materials about PID in the media
- We have set up an Instagram account to reach teenage audiences with our content
- We were trying to remind the importance of social distancing and social responsibility



immun@protect









WOLD PI WEEK

Ewa Kanuścińska

Cobacz statystyki.

Promu



### Last but not least

Instead of face-to-face meeting we have introduced the webinar form with GREAT SUCCESS



### To sum up

- The main patients' concerns in Poland were:
- no reliable scientific data concerning SARS-CoV-2 virus at the begginig of the pandemic
- 2) confusion caused by the lack of clear rules during a pandemic
- 3) mental disorders and stress caused by the lockown
- 4) fear for the future of the treatment
- 5) many questions related to work, school and life in the new reality



### To sum up

- The main role of our patient organisation during pandemics:
- transferring reliable scientific knowledge and cooperation with professionals in order to create clear and transparent rules for the patients
- 2) introduction of psychological support
- 3) taking care of the continuity of the IgG therapeutic program, constant contact with PID treatment centers and monitoring the availability of the IgG drugs
- presence in the media, organizing on-line meetings and webinars, constant contact with patients from all over the country



# Thank you for your attention







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#### **Cyprus Primary Immunodeficiencies and Friends**

## 14th IPOPI PID Forum - COVID-19 & Pandemics Management - Protecting the Most Vulnerable

Online Event

30<sup>th</sup> of September 2020

Secretary of Cyprus PID Association: Savvas Savva





#### **COVID19 in Cyprus**



First case announced on the 9<sup>th</sup> of March.

Public events cancelled on the 10<sup>th</sup> of March

Schools closed on the 13th of March

Work from home or closure of non essential business on the 16<sup>th</sup> of March

On the 24<sup>th</sup> of March, a complete national lockdown was enforced.

Reopening in 3 phases, starting on the 4<sup>th</sup> of May and completed on the 6<sup>th</sup> of June

Restrictions are still in place. The last few days there is an increase in cases.

Cases 1654 as of 22<sup>nd</sup> September, 'Deaths' 22. Cyprus Population 840,000







### **Protecting the Most Vulnerable – Problems faced**



**Initial Panic** 

Confusion fueled by media hype and 'misinformation'

Inconsistences in comments by doctors and 'specialists'

Restricted access to hospitals and supplies

Phycological issues

Number of PID patients in our Association, 7, (2), (1)

Till today no PID patient has been diagnosed with Covid19







### **Protecting the Most Vulnerable – Solutions**



In collaboration with doctors, hospital staff and the patients, therapies were shifted up to a couple of weeks and medication was provided. No serious problems occurred.

The patients and family members were informed continuously through our Facebook Group with all the government announcements and recommendations by the Health Ministry. Phone calls were made, if needed to have 'direct' contact.

We advised all our patients to work from home as soon as the 1<sup>st</sup> case was announced and be the last to return to work after the relaxation of the measures.







### **Protecting the Most Vulnerable – Solutions**



We encourage them not to completely isolate and get in touch if any kind of help was needed, even just talking, getting the groceries and take short walks around the neighborhood but keeping distances.

We advised to treat COVID19 as a very contagious and hostile flu bug and is not to be either underestimated or overestimated.

USE COMMON SENSE before acting and avoid spending too much time with the media hype and be careful with all the misinformation on the web, the conspiracy theories etc.







#### **Conclusions**



Being an island and the early measures of the government helped to restrict the spread of the virus. Unfortunately, it seems that the number of cases are on the rise. Opening of borders and the relaxed approach from the general public seem to be the main reasons.

The PID patients in Cyprus were not greatly affected but we still advise to be vigilant and follow the recommendations of the Ministry of Health as posted on our Facebook Group page. The association is in constant contact with the Ministry of Health, doctors, working together to ensure that our members are well informed and be prepared if a PID patient is diagnosed with Covid19.

### **THANK YOU**





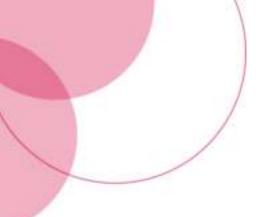




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# The role of patient organisations during pandemics

Anneli Larsson, Primär immunbristorganisationen, PIO, Sweden

### Sweden



#### **About PIO**

- Established 1978 by Maj-Lis Hellström
- Today 900 members (600 with PID)
- About 20 different PIDs represented
- Office with staff (3 persons, part time)

#### Overview covid-19 in Sweden

- First case: 31 January
- Recommendations: Keep your distance and take personal responsibility, stay home if you feel unwell, wash your hands often etc., recommendation regarding travels, extra precaution recommended for groups at risk of serious illness, (+ age 70 ect.)
- Restrictions: Ban to visit nursing homes, home study for upper secondary school, college and universities (during spring), ban on public gatherings of more than 50 people, legislation for restaurants, bars, etc
- Cases by Sept. 24: 90 289
- Deaths: 5 878

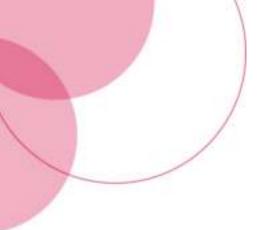




# Plan for the worst and hope for the best

### January-February 2020

- Prepared early to change our plans and way to work if the worst would happen.
- Incorporated digital technologies that were new to us in order to communicate with members and among board members (and wrote user friendly manuals in Swedish).
- Decided to hold all meetings digital more members than usual participated at our annual meeting in March!





# Challenges faced by persons with PID

### March 2020 – The pandemic was a reality

- Worry, fear, many questions to PIO by phone and e-mail.
- The whole world seemed uncertain, many people felt that the world was falling apart.

# Challenges faced by persons with PID



Am I at risk of having a severe covid-19 infection due to my PID?

If I get my "normal" infections, will there be room for me at the hospital?

Will I be able to get my Ig-treatment at the hospital?

Will I be safe from being infected with covid-19 at the hospital?

Should I move to a hotel if a family member gets covid-19?

Can I go to work and earn my living?

Will there be medicines available?

### Challenges faced by persons with PID



Am I at risk having a severe covid-19 infection due to my PID?

Will life ever be If I get my "normal" "normal" again? ections, will there be room for me at # hospita/

Will I and my spouse lose our jobs?

Will I be able to get

my lg-treatment at When can I see my

family and friends

again?

Sadness, frustration and depression due to isolation.

being infected with covid-19 at the hospital?

able?

Will there be How will I get my edicines groceries and will there be enough groceries for all of us?

hotel if a member gets covid-19?

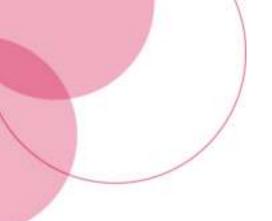
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# Our role as a patient org. during the pandemic

#### Meet the need for information and support members in isolation

- Several zoom meetings for adult members, lectures and possibility to ask questions to doctors, a nurse, a physiotherapist and a mental coach, small chat groups and craft meetings for children.
- WHO and the Public Health Agency of Sweden recommendations shared in our social media!
- Webinars with the opportunity ask questions to PID-specialists.
- Information about covid-19 on our website, in our newsletter and in social media.
- Special editions of our **podcast** about covid-19: medical information and member interviews: "The life in the shadow of covid-19".
- Office with staff: Possible for members to call or e-mail questions and to just talk.







- Huge need for valid information. But "We don't know yet" is an ok answer.
- In difficult times the need for patient organisations increase:
  - -members of all ages have been in contact.
  - -need to talk to someone and to "belong".
- Digital meetings bring us together makes it possible for members with severe conditions to participate that never have before....



# Lessons learned from the pandemic

- "Our" doctors and nurses in the eye of the pandemic storm difficult for us and members to get in contact.
- Lucky to have senior doctors who couldn't work at the hospitals due to covid-19. They provided PIO with information and helped us to answer questions from members and participated in webinars, Podcasts etc.
- IPOPI is really important! Wonderful job with information and webinars!
- Still a long way to go. It isn't over access to medicines and healthcare still at risk!

Collaboration between doctors, nurses, decision makers and patient organisations will be crucial to fight covid-19 and its consequences.





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# The challenges of pandemics from a medical and regulator's perspective

- Nathalie Bere, Patient Engagement, European Medicines Agency (EMA)
- Dr Nizar Mahlaoui, Necker-Enfants Malades Hospital (Paris, France) and Chair of IPOPI's Medical Advisory Panel



COVID-19 pandemic: challenges from the regulators point of view

IPOPI PID Forum "COVID-19 & Pandemics Management: Protecting the Most Vulnerable."





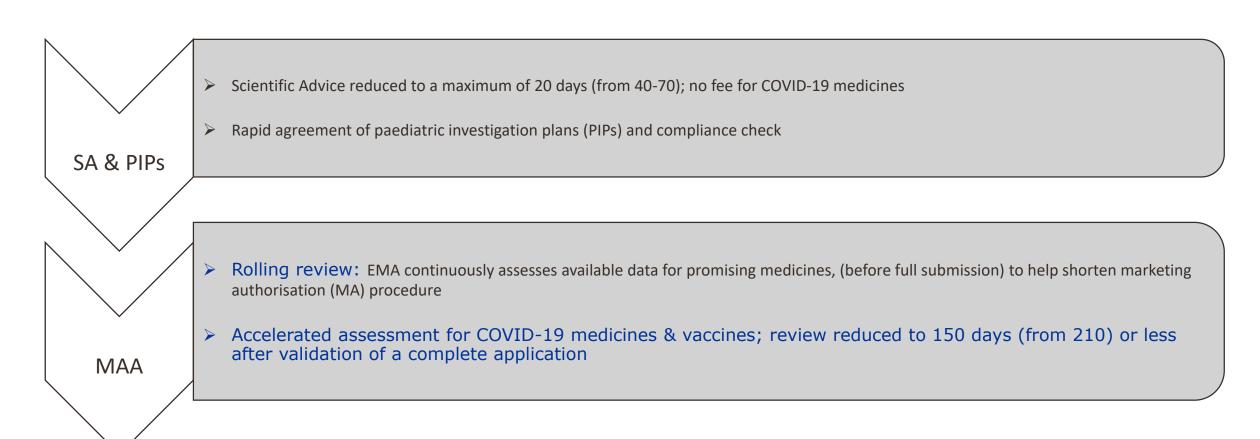
### COVID-19 challenges

- COVID-19 pandemic is a global crisis, with devastating health, social and economic impact.
- > There are no vaccines authorised yet to prevent any human coronavirus infections.
- The key challenge is to develop and approve, as quickly as possible, safe and effective **vaccines** to protect individuals.
- In the meantime effective **treatments** are still needed to manage COVID-19 symptoms and reduce deaths.

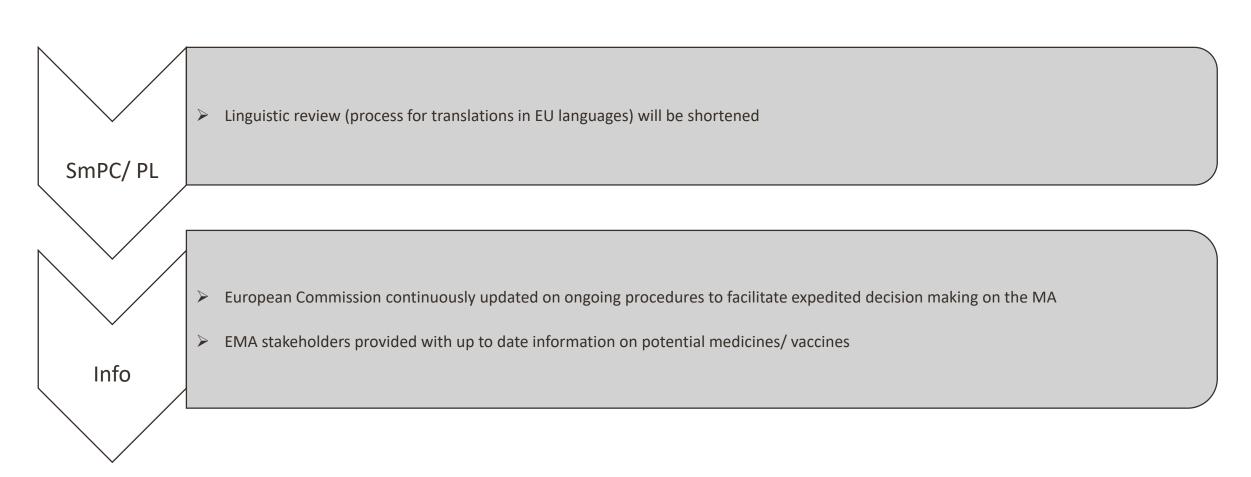
### Current situation and approach to COVID-19

- Huge worldwide efforts ongoing to develop medicines and make them available as soon as possible; several potential COVID-19 treatments and vaccines are undergoing clinical trials.
- COVID-19 vaccines and treatments must be rigorously tested and meet the same high standards in terms of safety, efficacy and quality, assessed by regulators who will only approve if the benefits are greater than any side effect or potential risks.
- EMA is contributing to global efforts by expediting its processes supporting the development and approval of treatments and vaccines and providing reliable information to patients and healthcare professionals.
- The <u>COVID-19 EMA pandemic Task Force</u> is a main tool for EMA and the EU medicines regulatory network to enable quick and coordinated regulatory actions. Patient and healthcare professional representatives are part of ETF.

# EMA support for development of treatments and vaccines (1)



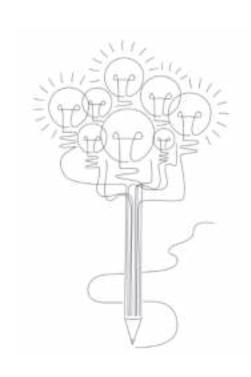
# EMA support for development of treatments and vaccines (2)



# Stakeholder engagement: critical for crisis management

- Engagement with patients and healthcare professionals is vital; stakeholder mapping, scenario-planning and impact assessment are critical elements
- EMA can engage rapidly and effectively via its network of patients and healthcare professionals
- Active dissemination of EMA COVID-19 communications is key to increase their effectiveness and ensure EMA is a trusted and regular source of reliable information for patients and healthcare professionals (and help dispel 'false news')
- > EMA will continue to hold COVID-19 information sessions for PCWP/HCPWP
- A pool of COVID 'patients' registered at EMA to ensure engagement during upcoming evaluation of medicines/vaccines

### Summary



- Key challenge is to develop and approve safe and effective medicines as quickly as possible
- EMA is supporting rapid development and approval of medicines by expediting its regulatory procedures
- EMA is providing up to date information to patients and healthcare professionals
- ➤ EU-wide regulatory network collaboration via EMA COVID Task Force
- International collaboration via ICMRA, WHO, FDA

### Any questions?



### Further information

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# COVID-19 & PANDEMICS MANAGEMENT: PROTECTING THE MOST VULNERABLE

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### The challenges of pandemics from a medical perspective

IPOPI 14<sup>th</sup> PID Forum | 2020, Sep. 30<sup>th</sup>
KNH/UoN A-Project Symposium on Primary Immunodeficiency Disorders:
"Towards Better PID Awareness, Early Diagnosis and Optimal Care"

Dr. Nizar MAHLAOUI, M.D., M.P.H., Ph.D.

French national Reference Center for PID (CEREDIH)

Necker-Enfants malade University Hospital

**IPOPI MAP Chairman** 





Contact: nizar.mahlaoui@aphp.fr

@MahlaouiNizar



# Background

- COVID-19 is a rapidly evolving situation
- Uncertainty about the impact of SARS-CoV-2 infection in individuals with rare diseases
  - Esp. patient populations intuitively at risk of developing severe, such as PIDs.
- Need for collaboration in gathering sound data, sharing informations, communicating

## **Global Statements & FAQ**

- 3 updates since Feb. 10<sup>th</sup>
  - Translation in many languages
  - English, Arabic, Slovenian, French, Spanish, Polish,
     Russian, Dutch
- International Medical Advisory Panel













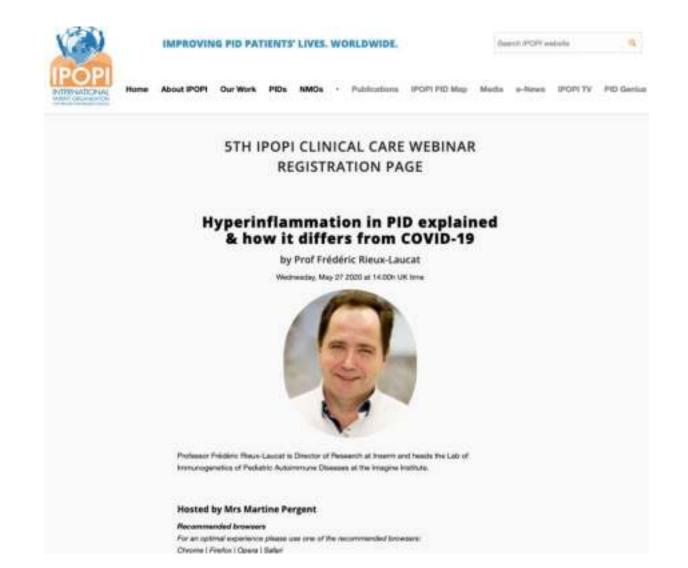








### **IPOPI COVID-19 Webinars Series**



### Collaborative international research efforts

Bucciol G et al. J Allergy Clin Immunol, 2020 Sep. 28th

- 94 patients worldwide
- Risk factors predisposing to severe disease and mortality: similar to the general population.
- Admission rates to ICU tended to be higher
- Median age lower than in the general population.

### COPID19 Worldwide survey of COVID-19 in PID patients

Home | All the patients |

COPID19

Worldwide survey of COVID-19 in PID patients > Home

## COPID19 Worldwide survey of COVID-19 in PID patients ClinicalTrials.gov Protocol Record: NCT04459689

With the emergence of SARS-CoV-2 and the COVID-19 pandemic, there is an urgent need to understand the impact of infection on immunodeficient individuals. Whilst co-morbidities (such as diabetes, cancer, arterial hypertension, heart disease...) have been documented in people infected with SARS-CoV-2, there is currently no information on the consequences and outcomes for individuals with primary immunodeficiencies (PID).

Following the 1st phase of the survey (launched by Isabelle Meyts (ESID), Nizar Mahlaoui (CEREDIH & IPOPI) and Kate Sullivan with Stuart Tangye (IUIS), that gave an idea of the number of affected PID patients and the impact of SARS-CoV-2 and directly focusing on obtaining this top level of information), we are launching the 2nd phase: "COPID19".

COPID19 survey is a secured online GDPR compliant platform based in Paris (Imagine Institute). It has been approved by the Paris-Necker-Enfants malades IRB and Ethics Committee. However, this retrospective survey is designed for global distribution. Data can be entered by a health care professional (mostly clinicians) through a personal login and password.

Each documenting person will have access to his/her own patients' data. COPID19 require a greater level of information than the 1st phase. The eCRF will be open to evolutions depending on progresses in our

Of course, all participating societies and organizations will be acknowledged for their help and input into this initiative. Thanks in advance for your invaluable contribution to this survey.

All the best,

#### The COPID19 team:

knowledge of this pandemic.

Nizar Mahlaoui (Paris-Necker, CEREDIH and IPOPI Chair of the IPOPI Medical Advisory Panel)
Fanny Lanternier (Paris-Necker and CEREDIH)
Isabelle Pellier (Angers and CEREDIH)
Alain Fischer (Paris-Necker, CEREDIH, Imagine Institute and Member of the IPOPI Medical Advisory Panel)
Benedicte Neven (Paris-Necker and Imagine Institute)
Jean-Laurent Casanova (Paris-Necker, Imagine Institute and Rockefeller University)
Klaus Warnatz (Freiburg-CCI and Member of the IPOPI Medical Advisory Panel)
Kate Sullivan (Philadelphia and IUIS)
Stu Tangye (Sydney, IUIS and Member of the IPOPI Medical Advisory Panel)
Isabelle Meyts (Leuven, ESID, IUIS and Member of the IPOPI Medical Advisory Panel)

# Management of patients

- Schooling/Workplace
- Access to Plasma Derived Medicinal Products (Immunoglobulins, WHO List of Essential Medicines) as PID patients have no alternative therapy
  - High dose regular Ig
  - Hyperimmune Ig
  - Convalescent plasma
- Access to vaccines (for patients and their entourage) herd immunity
- Psychological/Mental health issues (lockdown in children, etc...) Coping mechanisms
- Carry accurate informations to patients and caregivers + HCPs (GP, Nurses)
   + School teachers/Workplace HCPs





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# Lessons learnt from the pandemic

- Tomislav Sokol, Member of the European Parliament, EPP, Croatia
- Wolfgang Philipp, DG SANTE C3, Head of Unit of Health Security and Vaccination, European Commission





COVID-19 & PANDEMICS MANAGEMENT:
PROTECTING THE MOST VULNERABLE
30 September 2020
15:00 – 16:30

## Concluding remarks

Johan Prevot, International Patient Organisation for Primary Immunodeficiencies (IPOPI)





### 14th PID Forum

COVID-19 & PANDEMICS MANAGEMENT:
PROTECTING THE MOST VULNERABLE

September 30, 2020, 15:00-16:30

Virtual Forum
Hosted by:
MEP Tomislav Sokol
(EPP, Croatia)

