

ESC F BERLIN  
22.-25.05.2024

The Politics of Participation



Welcome to Berlin!



Organised by



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Welcoming address



**Jürgen Dusel**

The German Federal Government Commissioner  
for matters relating to Persons with Disabilities  
and patron of the ESCIF congress 2024

**Dear participants,**

Bringing together 32 organisations from 29 countries for a joint conference, that feat alone is worthy of high praise! The exchange of ideas at an international level is particularly important, as it gives us the opportunity to learn from the best. Looking beyond our national borders opens our eyes to new ideas and helps to stabilise our democracy.

Participation is a top priority for me. For me, it is the "operating system" of the UN Convention on the Rights of Persons with Disabilities. We are all familiar with the phrase "nothing about us without us", and we are all working together to make this principle a more tangible reality. This conference is an important part of achieving this goal. The expertise of people with disabilities is incredibly valuable, policy-makers and administrators should make good use of it. If we are serious about participation, we need to be persistent. I am very glad that there are opportunities like this conference to exchange ideas on strategies, legal options and possibilities for cross-border cooperation.

People who use wheelchairs, for whatever reason, are often marginalised in our societies simply because of the way we design our spaces. They have difficulty finding suitable work or housing and are generally restricted in their mobility. What good is it for you to have health insurance if you can't get to the doctor's office?

There is an urgent need for more participation in this regard, so that the visible and invisible barriers can be removed. I, too, am committed to help make this happen.

I wish all of you a productive conference and I hope that you will return to your home countries with a renewed sense of energy!

*Dear delegates, dear participants and speakers,*



We are delighted that you are joining us for the 2024 ESCIF Congress held in the beautiful city of Berlin. FGQ have worked extremely hard to ensure a engaging Congress with a theme that will inform and inspire. Political participation of persons with disabilities is crucial for shaping policy and legislation on disability-related issues at national and European levels. We can offer first-hand experience and specialised knowledge with expertise that lead to more effective policies as well as fostering cohesion and solidarity. We invite you to explore this theme of political participation with fellow member organisations and help push forward the agenda for greater inclusion and representation within the European political landscape.

Lucy Robinson, ESCIF President



It is our great pleasure to welcome you in Berlin, the political and cultural capital of the Federal Republic of Germany. A lively city steeped in history and diversity, which today is home to nearly 4 million people of different religions, ethnicities and cultures. We meet during the celebrations to mark the 75th anniversary of the German constitution, which amongst other things stipulates that no person shall be discriminated against on the grounds of their disability. A first step on our long journey towards equality and inclusion. I hope the ESCIF congress 2024 will continue along this path in successfully creating a joint political force across all ESCIF member organisations. Let's roll on together into a more inclusive world.

Kevin Schultes, FGQ Chairman



## Jürgen Dusel

is a German lawyer and has been the Federal Government Commissioner for matters relating to Persons with Disabilities since 2018. The motto of his term of office is „Democracy needs inclusion“ with a focus on accessibility in all areas of society as well as comprehensive opportunities for political and occupational participation. Jürgen Dusel is patron to the ESCIF congress 2024.



## Vincenzo Falabella

is a political advisor to the Italian government for the interests of people with disabilities. As the president and legal representative of the Italian Federation for Overcoming Disabilities (FISH), he executes the resolutions passed by the Congress and the National Council. He was appointed by the Prime Minister Meloni and the President of the Republic Sergio Mattarella as advisor to the National Economic and Labor Council.



## Christof Fiscoeder

has 20 years of professional experience in international strategic and corporate communications, public affairs and online communications. He has been an independent consultant since 2012 working and campaigning amongst others for the German Medical Technology Association (BVMed), various associations and corporate alliances.



## Kira Grünberg

started doing athletics at the age of 7. After four years of trying all the different disciplines, she knew that pole vaulting was the right choice for her. Kira was voted Austrian track and field athlete of the year 2014. One year later she broke her fifth cervical vertebra during a training jump. She has been a member of the Austrian Parliament and a spokeswoman for people with disabilities and inclusion since November 2017.

# Speakers



## Humberto Insolera

is a distinguished figure in disability advocacy, having served on the Executive Committee of the European Disability Forum for many years. With expertise in diverse policy areas, he contributes significantly to global discussions on disability rights and inclusion. Recently, Humberto has been nominated as a candidate for the European Parliament.



## Katrin Langensiepen

has been representing Lower Saxony and Bremen in the European Parliament since 2019. As social policy spokesperson for Greens/EFA and one of the few MEPs with a visible disability, she uses her voice to fight for a green, social and inclusive Europe. She believes now is the time to think environmental and social policy together.



## Frans Penninx

earned a MBA at University of Groningen in 1982. He started work as assistant professor at Erasmus University in Rotterdam. After founding, building and staffing the new Rijndam Rehabilitation Center (incl. SCI department) in Rotterdam, he was CEO of home care organizations and the CFO of a large mental health institution. He was a board member of the Dutch SCI Association from 2009 until 2018 and has been advisor to the board since then.



## Matthias Rösch

was Commissioner for the matters of people with disabilities in Rhineland-Palatinate (2013–2023) and co-founder of the Center for Independent Living for people with disabilities in Mainz. He is a graduated psychologist and trainer for peer counseling. Activities in local politics of the city of Mainz (city council, disabled advisory board).

# Program

## Wednesday, 22rd May 2024

Scandic Hotel, Gabriele-Tergit-Promenade 19, 10963 Berlin

17:00 – 18:00	Congress Registration
18:00 – 19:00	Welcome Drink
19:00	Dinner

# Restaurant



8:30 – 9:30 **Transfer Scandic Hotel – Aletto Hotel**  
Aletto Hotel Potsdamer Platz,  
Luckenwalder Str. 12, 10963 Berlin

9:30 – 10:00 **Welcome / Introduction**  
**Lucy Robinson and Kevin Schultes**  
**Keynote:**  
**“Nothing about us, without us – People with disabilities fighting for their rights”**

**Matthias Rösch**  
Former Commissioner for the matters of people with disabilities in the state Rhineland-Palatinate

10:00 – 11:00 **Examples of political Work**  
**Humberto Insolera**  
A distinguished figure in disability advocacy, serving on the Executive Committee of the European Disability Forum

live via video

**Vincenzo Falabella**  
Political advisor to the Italian government for the interests of people with disabilities

11:00 – 11:30 Coffee break

11:30 – 13:00 **Examples of political work**

video clip

**Katrin Langensiepen**  
German politician and member of the European Parliament

**Kira Grünberg**  
Former professional athlete and member of the National Council in Austria

**Frans Penninx**  
Former member of the board of the Dutch SCI Association

**Panel discussion with speakers**

13:00 – 15:00 Lunch break  
**Optional transfer**  
Aletto – Scandic – Aletto (14:00 – 16:30)

15:00 – 17:00 **Afternoon session**  
Discussions with speakers

17:00 – 17:30 **Presentation Lifeward / Coffee break**

17:30 – 18:00 **Workshop preparation**  
**Matthias Rösch and Kevin Schultes**

18:00 – 19:00 **Evening workshop lobbying**

**Christof Fischoeder**  
Consultant and campaign manager to industry, associations and institutions

19:00 Dinner (Aletto Hotel)

21:00 **Transfer Aletto – Scandic**

Optional: Night walk

22:00 Film and light projection, Marie-Elisabeth-Lüders-Haus



Thursday, 23rd May 2024

# Workshop

## How to lobby? Representation of institutional and personal interests in health care politics

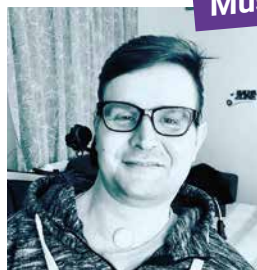
We will show easy and hands-on ways to bring interests and ideas into the field of health care politics. We will show examples from messaging via stakeholder relations management up to creating your own campaign.

Are you in need to contact your member of parliament? Do you need to enforce political pressure on the health insurance for a better care? Or do you have other specific challenges in representing your interests towards stakeholders of the European health care systems?

Then this workshop will be a place to learn and discuss!

### 18:00 – 19:00 / Content:

- How to lobby?
- Who to talk to?
- What is your message?
- How can you get in contact?
- Examples of lobbying and stakeholder relations
- Ask us anything



Music: DJ's Tetrastyle and Stralle

# Program

Friday, 24th May 2024

8:30 – 9:30

**Transfer Scandic Hotel – Aletto Hotel**

9:30 – 10:00

**Welcome Speech**

**Jürgen Dusel**

German Federal Government Commissioner for Matters relating to Persons with Disabilities and patron to ESCIF congress 2024

10:00 – 11:30

**Workshops on political work**

**Lucy Robinson, Christof Fiscoeder, Matthias Rösch and Kevin Schultes**

11:30 – 12:00

Coffee break

12:00 – 13:00

**Plenary session – results of workshops – planning future activities**

Discussion

13:00 – 15:00

**City tour experience**



15:00 – 16:30

Visit to Federal state representation Rhineland-Palatinate

16:30 – 17:00

**City tour experience / Congress photo**  
Brandenburg Gate

17:30

**Transfer Brandenburg Gate – Scandic Hotel**

19:00

**Congress dinner** at Scandic Hotel

# Members Input



## Gunilla Åhrén

is head of the Gothenburg Centre of Excellence for Spinal Cord Injuries. The physiotherapist has lived with spinal cord injury for 30 years, has worked for the Swedish SCI consumer organisation and was Vice President of ESCIF.



## Daniela Vozza

has been head of Life Counselling at the Swiss Paraplegic Association since April 2020. The qualified social worker previously worked in social counselling at the Swiss Paraplegic Centre.

## Lifeward – The next step in exoskeletal care

Lifeward is a leading provider of innovations that support people with physical limitations or disabilities to achieve life-changing results and help them achieve outcomes they never thought possible.

With our ReWalk Personal Exoskeleton, we provide persons with spinal cord injuries a new level of independence with life changing robotics.

Thursday, 17:00 – 17:30



# Program

Saturday, 25th May 2024

Scandic Hotel  
Gabriele-Tergit-Promenade 19  
10963 Berlin

9:30 – 11:00

**Assembly**

11:00 – 11:30

Coffee break

11:30 – 13:00

**ESCIF members input**

**An interactive online course for consumers and rehabilitation staff now available in English language**

**Gunilla Ahren**

**Initiative for an inclusive Switzerland  
Daniela Vozza**

**Update on situation in Ukraine  
Serhii and Nataliya Bolchuk**

**ESCIF Congress 2025**

**Conclusions / Closing**

13:00 – 15:00

Lunch

**Have a safe journey home!**

### What are good examples of political work and taking influence – at European, national, state and local level?

10:00 – 11:30

#### Teamwork

What would you like to achieve politically?

How can this be realised, which activities are necessary and how can ESCIF help to achieve this?

12:00 – 13:00

#### Presentation of the workshop results, discussion



#### Matthias Rösch: “Nothing about us, without us – People with disabilities fighting for their rights”

Based on the history and philosophy of the independent living movement of people with disabilities, Matthias will discuss the human rights-orientated approach of the UN Convention on the Rights of Persons with Disabilities (CRPD). How have the consumer organisations of people with disabilities influenced social change and political processes - what milestones and important actions have there been and still are in place? He will also show examples of European and national legislation and the influence of and the impact on people with disabilities. How this has led to more self-determination, empowerment, inclusion and accessibility.

#### Humberto insolera: “Empowering Participation: EDF’s Political Engagement in EU Accessibility Policy”

Over the last years, the European Union has adopted important legislation to promote accessibility in different fields. From the Audiovisual Media Services Directive to the European Accessibility Act, we have now a comprehensive legal framework in place. In this keynote speech, Humberto Insolera, Executive Member of the European Disability Forum, will provide an assessment of these initiatives from the perspective of the disability community. He will also outline future challenges and propose strategies to address them effectively.

#### Vincenzo Falabella: “The role of the associations in the constitutional framework”

The disability world is not a world apart. It is a part of the world. Vincenzo will start from these words to outline a definition of what the term ‘disability’ means today and to explain how, for eighteen years, i.e. since 2006, there has been a real change, enabled by the approval of the UN Convention on the Rights of Persons with Disabilities. This first UN Convention of the new millennium became Italian Law in 2009. Vincenzo Falabella reports on the work of the FAIP-Ets and will outline the impact that this law has had on politics, regulations, welfare and last but not least on language since.



### **Katrin Langensiepen: “Policies for people with disabilities**

Katrin Langensiepen will give a practical insight into the work as a Member of the European Parliament and report on the current status of the European Parliament’s work in the field of policies for people with disabilities, with a focus on the implementation of the UN CRPD. She will present information on the recent introduction of the EU disability card, the successful establishment of the accessible EU-centres in the member states and the efforts of the UN expert committee to assess the implementation of the UN CRPD.

### **Kira Grünberg: “My jump into a new life”**

Kira Grünberg talks about how she accepted her new life as it is, what gave her hope and courage to face new challenges and what character traits are necessary to lead a happy life despite a severe stroke of fate. In her talks, she wants to reach people struggling with a similar fate and raise awareness of the topic of inclusion among the general public. After all, inclusion is the only way to foster everyone’s talents and potential to achieve more together.

### **Frans Penninx: “Dutch examples of political work”**

DON, the Dutch SCI Association was founded in 1976 and is the only national stakeholder for people with a SCI. The organisation has three core tasks: providing information, advocacy in healthcare (SCI) policy and laws and peer support. Political work is executed on DON’s own initiative and/or in partnership with Dutch umbrella organisations. Frans will give examples of successful petitions and campaigning for e.g. catheter reimbursement and adequate wheelchair provision.

### **Daniela Vozza: “Initiative for an inclusive Switzerland”**

In Switzerland, citizens have the right to start initiatives to change the constitution on the communal, state and the federal level. This inclusion initiative calls for a self-determined life for the 1.7 Million people with disabilities in Switzerland

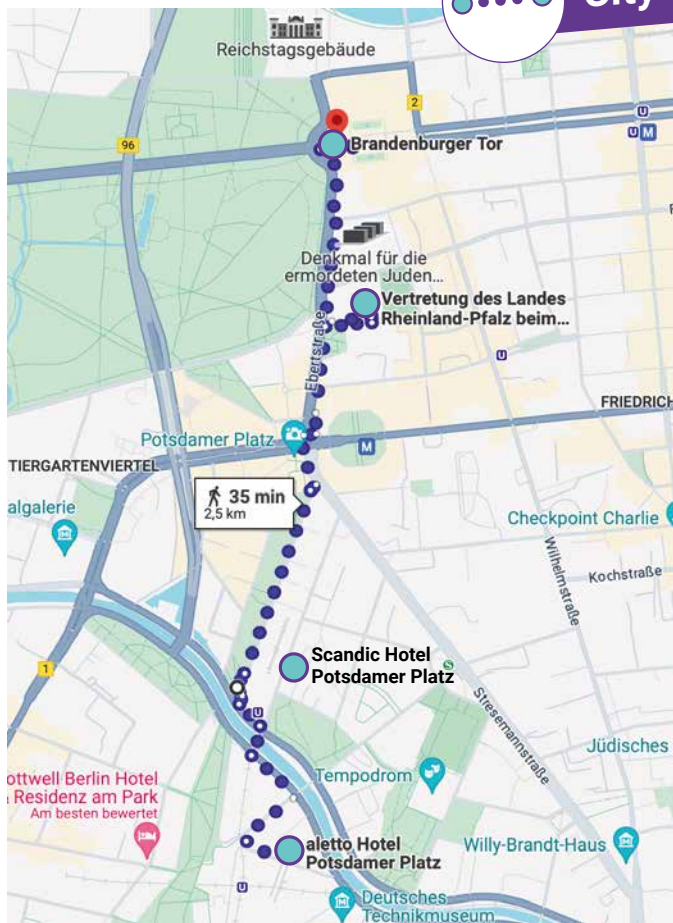
There has been a ban on disability discrimination in our constitution for 23 years. Switzerland has also ratified a law on equality for people with disabilities and the UN Convention on the Rights of Persons with Disabilities. Nevertheless, people with disabilities do not have the same access to human rights as non-disabled people.

### **Gunilla Ahren: “An interactive online course for consumers and rehabilitation staff now available in English language”**

There’s a need to improve theoretical knowledge of spinal cord injuries (SCI) in newly injured persons as well as staff at rehabilitation units, where new staff is being employed continuously. The knowledge needs to be always accessible and easy to understand without much guidance. The Gothenburg Competence Centre for Spinal Cord Injury has produced an online course to meet this need. The online course is now translated in English and free of charge.

# Map

## City tour



### Conference addresses:

#### Scandic Hotel Potsdamer Platz

Gabriele-Tergit-Promenade 19, 10963 Berlin

#### aletto Hotel Potsdamer Platz

Luckenwalder Str. 12, 10963 Berlin

#### Representation of the State of Rhineland-Palatinate to the Federal Government and the European Union

In den Ministergärten 6, 10117 Berlin

# Berlin sight seeing

Berlin has often been the scene of world history – for example, when the Wall came down. You can discover traces of history everywhere in Berlin.

Berlin is also a city for shopping – in addition to luxury shopping on Kurfürstendamm, you will also find numerous flea markets throughout the city. From the Reichstag parliament building to Alexanderplatz. From Gendarmenmarkt square to the Museum Island. Berlin is full of surprising things to discover. And surprisingly easy to travel around when it comes to accessible things to do in the city

For Berlin's accessible top sights scan the QR code:



FGQ  
Emergency contact/  
WhatsApp:  
+49 172 4777667





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Zagreb, Croatia

Hotel Westin

