

## REPORT OF EUDF ACTIVITIES AT EASD ANNUAL MEETING

Looking back at an exciting #EASD2024 full of science, exchange and commitment of all stakeholders to optimize the outcomes for people with diabetes we are now summarizing the multiple initiatives of EUDF on such an occasion.

The mission of EUDF is to ensure the translation of research into policy actions. We are particularly happy to see an increasing interest from politicians, regulators, representatives of WHO Europe and European Commission project leaders to attend sessions and mingle with researchers, clinicians and people with diabetes.

EUDF was present with a booth in the Corporate Village Plaza and has organized several symposia and activities.

The EASD President and EUDF vice-chair Chantal Mathieu referred to the work of EUDF over the past year in her Presidential Address and thanked all EUDF Members and Supporting Collaborators for their continuous collaboration and engagement.



## These the EUDF initiatives and activities at the 60th Annual Meeting of the EASD

*September 9*

### **EUDF WORKSHOP - Diabetes Data & Registries**

Exciting times in Madrid. EUDF kicked off hashtag EASD2024 with a workshop on Diabetes Data and Registries.

The objectives of the workshop were:

- share best practices,
- optimise the clinical use of existing registries to improve outcomes for PwD
- inspire countries that plan to set-up a registry
- advice on registry implementation.

More than 30 experts in representation of national, European and global registries discussed challenges and opportunities they have encountered in setting up their registries and diabetes database and how diabetes registries can enable high-quality diabetes care.

Participants:

Astrid Lavens, Kalina Todorova (Belgium – Sciensano)  
Thomas Danne (Breakthrough T1D)  
Massimo Massi Benedetti (CHIEF)  
Rob Heine (EFPIA - Eli Lilly)  
Stefano Del Prato, Bart Torbeyns (EUDF) Federico Serra (EUDF Italy)  
Hélène Hanaire (France - SFDT1)  
Juliana Chan (Hong Kong Diabetes Register),  
Elisabeth Dupont (IDF Europe)  
Sean Dinneen, Karina Hamilton, Collette Tully, (Irish Diabetes Registry),  
Antonio Nicolucci, Giacomo Vespasiani (Italy - Annali AMD),  
Hector Bueno (JACARDI EU Commission Joint Action CVD and Diabetes)  
Silvia de Vries (Netherlands – DPARD),  
Helen Colhoun (Scottish Care Information – Diabetes Collaboration),  
Xavier Cos, Bogdan Vlacho (Spain – SIDIAP)  
Katarina Eeg-Olofsson (Swedish National Diabetes Register),  
Olga Kordonouri (SWEET)  
Kamlesh Khunti, Dipesh Patel (UK – NHS Audit)  
Jill Farrington (WHO Europe, Regional Medical Officer, CVD and Diabetes)  
Fleur Levrat (MedTech Europe – Abbott)  
Rob Brines (Bite Medical)

All participants dealt with a series of questions over 2 sessions chaired by Stefano Del Prato and Robert Heine.

Round 1:

What was the purpose of the registry / data set?

Who were involved, and how were you supported?

What were the basic requirements to initiate your registry?

What was the most important barrier in building the registry, and how did you overcome it?

Successes and challenges? Does the registry fulfill the expectations?



Round 2:

Was your registry designed for research/epidemiology purposes or to facilitate diabetes care?

How did the registry affect diabetes care and the outcomes for people with diabetes?

If you manage a research registry, would you be willing to leverage your research registry for clinical purposes? And, what would be required to accomplish this?

What are your aspirational goals for the registry?

The discussion was captured by Rob Brines from Bite Medical with the intention to generate a meeting report that will be supported by a short written document prepared by all participants and that will be made available on the EUDF website.

September 11

**EUDF Symposium - Diabetes Registries: Enabling high quality diabetes care**

## Diabetes data and Registries: *Enabling high quality diabetes care*

### PROGRAMME:

- Welcome and introduction
- Why Registries?
- The different roles of registries in research and diabetes care
  - Clinical: Hong Kong Diabetes Register
  - Research: European pre-T1D Registry
  - National: Swedish National Diabetes Register
  - Care: SWEET Registry
- Round Table: how to leverage existing research registries for clinical purposes
- The policy perspective on data and registries
  - WHO EURO: How to measure and monitor progress towards the global diabetes targets
  - EU Commission: Collaborative Health Information European Framework (CHIEF)
  - JACARDI: Data availability, quality, accessibility and sharing
  - European Regulator: Opportunities and challenges of registries for regulatory decision-making
- Q&A, Wrap-up & next steps

SEPTEMBER 11

RETIRO HALL

14:00-16:00 CET



Stefano  
Del Prato



Kamlesh  
Khunti



Juliana  
Chan



Anette  
Ziegler



Katarina  
Eeg-Olofsson



Olga  
Kordonouri



Robert  
Heine



Jill  
Farrington



Massimo  
Massi  
Benedetti



Hector  
Bueno



Carla  
Torre



Chantal  
Mathieu



European  
Diabetes Forum



In the EUDF symposium, Kamlesh Khunti presented the recent EUDF recommendations on data registries to introduce the session. This work is the result of extensive work with all EUDF members and supporting collaborators EASD, EFSD, FEND, Breakthrough T1D, IDF Europe, SFD, ISPAD, PCDE, EFPIA and MedTech Europe.

Stefano Del Prato chaired the session on the different roles registries play in research and diabetes care with Juliana Chan sharing best practices from Hong Kong, Katarina Eeg-Olofsson from Sweden, Olga Prof. Dr. Kordonouri from SWEET, and Anette Ziegler from the European Pre-T1D Registry.

The insights from the Monday workshop were presented by Robert Heine who also moderated the round table.

Chantal Mathieu chaired the session on the policy perspectives that different stakeholders have on data and registries. Dr Jill Farrington from WHO EURO presented how they plan to measure and monitor progress towards the global diabetes targets, Massimo Massi Benedetti from the EU Commission's Collaborative Health Information European Framework (CHIEF) project



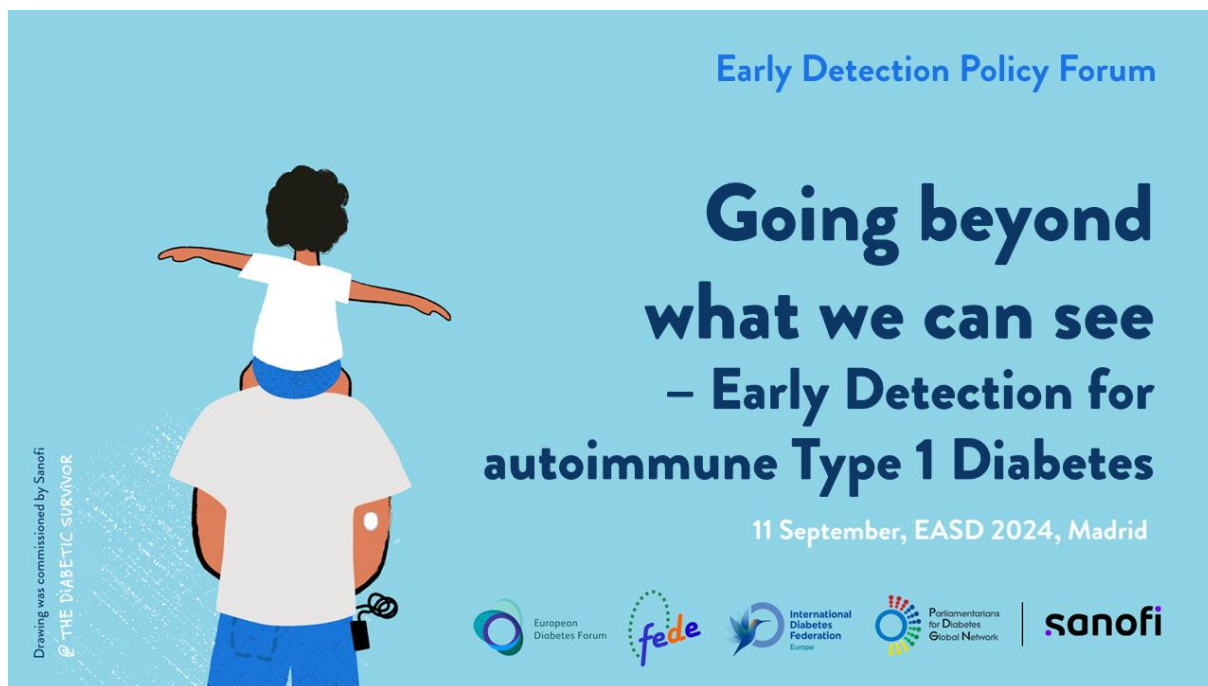


gave an update on its activities, the Joint Action JACARDI project initiated by the European Commission was introduced to the diabetes community by the Work Package Leader Héctor Bueno, who presented the objectives of the work package on data availability, quality, accessibility and sharing. Finally, Carla Torre provided the European regulator's perspective on data registries and RWE for regulatory decision-making and how these registries can complement insights from randomized clinical trials.

The recording will be available on the EASD Annual meeting platform and on the EUDF website.

Spoiler alert: we need more and especially better quality data for research, policy-making and care.

### Early Detection Policy Forum organised by EUDF, IDF Europe, PDGN, FEDE, Sanofi

The poster features a light blue background. On the left, there is an illustration of a man in a grey shirt and blue pants carrying a young child with dark skin and curly hair on his shoulders. The child is wearing a white shirt and blue shorts, and has their arms outstretched. To the left of the illustration, vertical text reads 'Drawing was commissioned by Sanofi' and '@THE DIABETIC SURVIVOR'. On the right side, the title 'Early Detection Policy Forum' is at the top in blue. Below it, the main text 'Going beyond what we can see – Early Detection for autoimmune Type 1 Diabetes' is in large, bold, dark blue letters. Underneath the title, the date and location '11 September, EASD 2024, Madrid' are written in a smaller font. At the bottom, there are five logos: the European Diabetes Forum logo, the FEDE logo, the International Diabetes Federation Europe logo, the Parliamentarians for Diabetes Global Network logo, and the Sanofi logo.

EUDF, in collaboration with the co-organizing partners IDF-Europe, Federación Española de Diabetes (FEDE), Parliamentarians for Diabetes Global Network (PDGN) and Sanofi, fostered this event to raise awareness on changes needed to ensure access to screening programs for Type 1 diabetes across the world by establishing a Early Detection Policy Forum.

This unique event brought together government representatives, policy makers and key patient associations from across the world, fostering a rich conversation on how to join forces and innovate the field of T1D detection and management.

EUDF fully supported this initiative as was represented by different members: Pinar Topsever (PCDE), Sufyan Hussain & Tadej Battelino (IDF Europe), Chantal Mathieu (EASD) and Bart Torbeyns (EUDF).

To learn more about our work in T1D, visit <https://www.eudf.org/our-work/screening-and-detection/>



Following the success of the Early Detection Policy Forum, we are delighted to share this joint call to action to boost EU policies to ensure early detection for T1D published by Euractiv. While screening initiatives across countries are gaining momentum, without a coordinated approach and the policy infrastructure to support it, local healthcare systems cannot support the standardization and scaling of such practices within clinical care.

EU policies must support unified action by Member States, including awareness campaigns around the importance of an early T1D diagnosis, as well as timely access to innovative therapies to all at risk of and living with T1D.

Read more about T1D and early detection in: <https://www.euractiv.com/section/health-consumers/opinion/type-1-diabetes-can-be-fast-but-we-can-be-faster-a-call-to-boost-early-detection/>

September 12

## **EUDF Spotlight Session - AI Driven Clinical Decision Support Systems (AI-CDSS): Potential, concerns and should it bring to people with diabetes?**



**EASD 2024**

**Sept 12 14:00-14:45 CET Spotlight Stage**

### **AI Driven Clinical Decision Support Systems:**

*Potential, concerns and what should it bring to people living with diabetes?*



Welcome and Introduction  
*Stefano Del Prato*



Implications of using AI-CDSS in diabetes care  
*Alfonso Galderisi*



What should AI-CDSS deliver in diabetes care?  
*Peter Schwarz*

European Diabetes Forum

In this session, the potential and concerns of AI driven clinical decision support systems were discussed by Stefano Del Prato, Peter Schwarz and Alfonso Galderisi. The consensus statements of the EUDF working group were presented.

Alfonso Galderisi highlighted the potential

of AI in diabetes management and Peter Schwarz presented some existing AI implementations such as Mebix in Germany and Doctors AI in India, as a model how to use AI in the hands of healthcare professionals to improve diabetes care.

Main messages of the Session were:

- AI driven clinical decision support systems should facilitate patient-centered care and empower healthcare professionals.
- AI requires robust regulation and privacy safeguards, data standards and sharing, optimal clinical data capture.

The work and full consensus statements will be published soon.





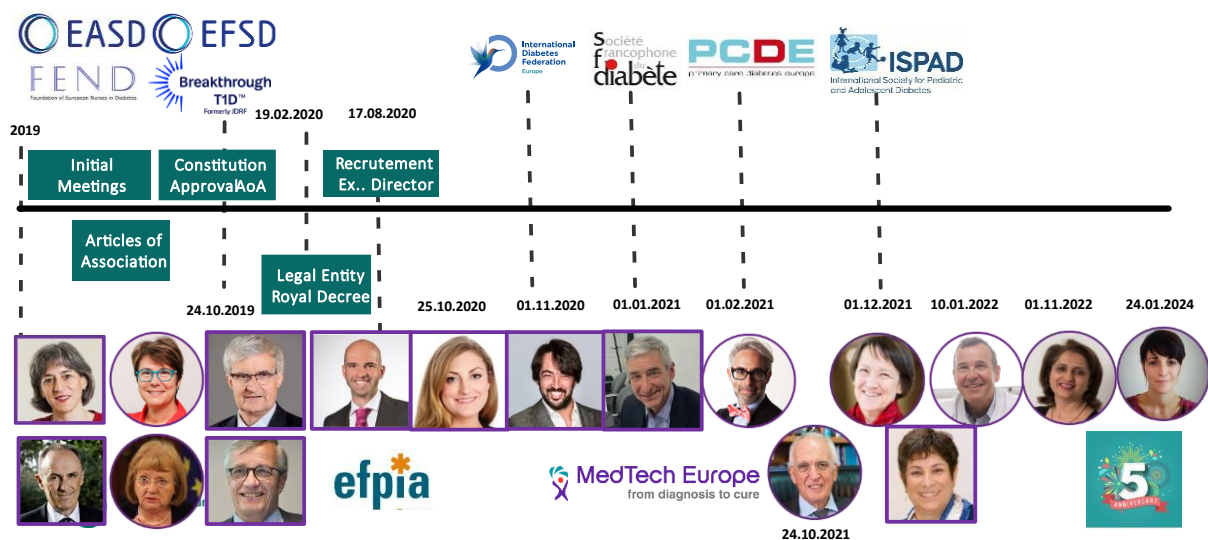
## 5 year celebration EUDF: the past, the present and the future

EUDF celebrated its 5 year of activity with a networking reception and overview of how it all started by Juleen Zierath, the initial years by Chantal Mathieu, the current roadmap and projects by Stefano Del Prato and next steps by Bart Torbeyns. The final word was for Bastian Hauck who reflected on the early days and called for an ongoing collaboration with all diabetes stakeholders for the benefit of people living with diabetes.





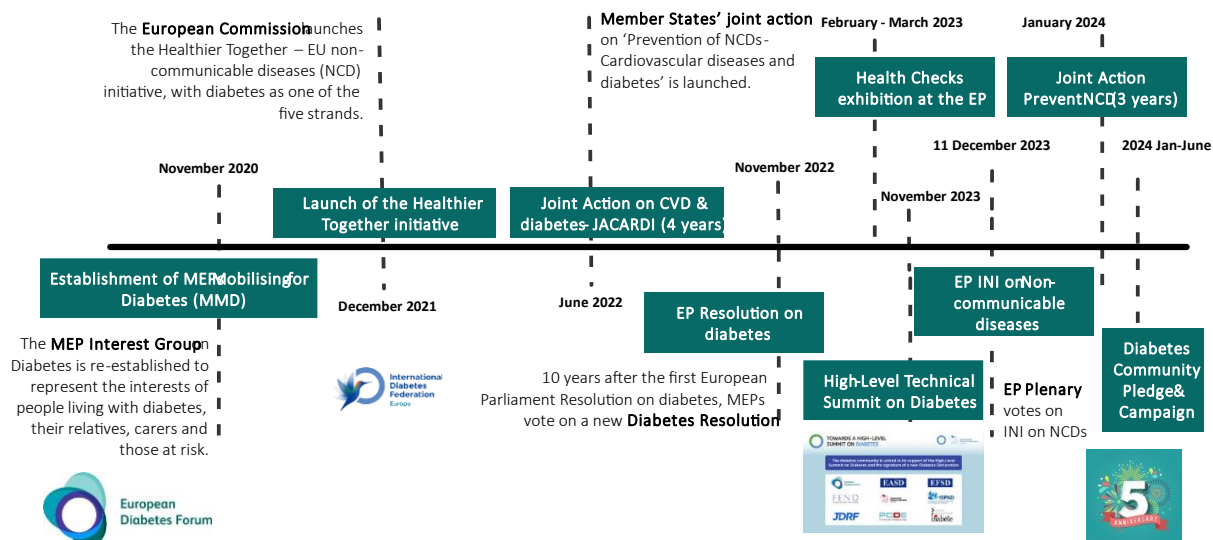
## KEY PEOPLE, MEMBERS AND SUPPORTING COLLABORATORS



## KEY PROJECTS AND ACTIVITIES



## KEY POLICY MILESTONES AND ACHIEVEMENTS



The session was concluded with thanking all EUDF Members, Breakthrough T1D, EASD, EFSD, FEND, IDF-Europe, ISPAD, PCDE, SFD and Supporting Collaborators EFPIA & MedTech Europe for their support and commitment to the work and activities of EUDF.