IF Information Package on the European Union
Introduction

The International Federation for Spina Bifida and Hydrocephalus (IF) advocates for the rights of individuals with Spina Bifida and Hydrocephalus (SBH) and their families and the implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) worldwide.

As a part of that mission IF represents the SBH community in advocacy to the European Union (EU). Furthermore, as an important international actor the policies and actions of the EU have a global relevance. A good understanding of political institutions is essential for effective advocacy and IF strives to empower national SBH associations and individuals with SBH and their families to take part in shaping EU policies.

In this IF information package the core institutions of the EU and how they relate to disability rights in the EU are outlined.
What is the European Union?

The EU is an international organisation of 27 European countries. In the EU the Member States enact joint legislations and funding programs to guarantee the free movement of people, goods, services and capital between countries. It is the fundamental goal of the EU to continuously enhance the freedom and prosperity of all its citizens. EU legislation has significantly advanced the rights of persons with disability in Europe and worldwide.

The EU has four core institutions:

- The European Commission
- The Court of Justice of the European Union
- The European Parliament
- The European Council (not to be confused with the Council of Europe).

These institutions have different roles in the EU policy making process and provide different ways for citizens to engage with their work. The specifics of what the EU institutions are and are not allowed to do is laid out in the Treaties.

The core functional treaties are:

- The Treaty on the European Union (TEU)
- The Treaty on the Functioning of the European Union (TFEU)
The European Commission

The European Commission is the executive body of the EU and has a variety of functions. The Commission drafts new initiatives, directives and legislation, which is submitted to the European Parliament and finally the European Council for approval. The Commission also manages different programmes including funding programmes.

However, the Commission is limited in regards to what it can take action on and how. The word ‘competency’ is used to describe who has the power to take action. The Commission is limited in what it can do in areas where it has no competence, for example it cannot force the Member States to build more schools or hire more teachers.

Important EU legislations include:

- Directive 2011/24/EU on patients’ rights in cross-border healthcare
- Directive (EU) 2019/1158 on work-life balance for parents and carers
- Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation

However, even when the Commission or other EU institutions may not have full competency they will often issue recommendations or create opportunities for European collaboration and exchange of good practices such as:

- The European Reference Networks (ERNs)
- The EU Health Policy Platform.

Other important publications and projects relevant to SBH created and/or managed by the Commission include:

- The Strategy For the Rights of Persons with Disabilities 2021-2030 outlines the actions which the Commission intends to take as well as recommendations to the Member States at the European Council
- The Green Paper on Ageing
- The European Child Guarantee
The Commission is led by a group of 27 Commissioners from each Member State, also known as ‘the college’ which is led by the President of the European Commission. New Commissioners are appointed every five years.

Each Commissioner is given a specific role or topic which they are in charge of. For example, equality or health and food safety. In addition, the Commission has different departments, these are called Directorates-General or DGs.

DGs most relevant to the work of IF include:

- DG EMPL – Directorate General for Employment, Social Affairs and Inclusion
- DG SANTE – Directorate General for Health and Food Safety

The Commission also has executive agencies which manage programmes set up by the Commission. For example, the European Health and Digital Executive Agency (HaDEA) which manages the EU4Health Programme.
The Court of Justice of the European Union reviews whether the EU institutions have acted in accordance with EU law, that Member States are fulfilling their obligations and makes judgements on the interpretation of EU law in order to facilitate consistent application of the law in all national courts and tribunals within the EU.
The European Parliament is composed of Members of the European Parliament, also known as MEPs and are elected by European citizens during European elections.

The purpose of the European Parliament is to represent citizens. Just like in national parliaments MEPs work together in different European political parties or groups. There are currently seven political groups in the European Parliament, the three biggest are the European People’s Party (EPP), the Socialists and Democrats (S&D) and Renew Europe.

Within the European Parliament there are several Committees which discuss specific issues. For example, there is the Committee for employment and social affairs also known as the EMPL Committee. This committee handles a lot of very important initiatives relevant to individuals with SBH. Another important committee is the ENVI committee which stands for Environment, Public Health and Food Safety.
The European Council sets the EU’s overall political direction and priorities. The members of the European Council are the heads of state of the Member States, as well as the European Council President and the President of the European Commission.

As a part of this institution there is also the Council of the EU, this is where national ministers from the Member States meet to adopt laws and coordinate policies.

The Council of the EU is also divided into smaller Councils according to topics. For example the Employment, Social Policy, Health and Consumer Affairs Council which discusses the policies most relevant to the SBH community.
The role of IF

As an umbrella organisation for SBH associations from all over the world IF plays an important role in advocating for the rights and needs of individuals with SBH and their families to the EU.

IF achieves this by:

- Connecting with and lobbying to EU policy makers
- Participating in public consultations
- Participating in stakeholder consultations
- Publishing reports and statements on EU policies
- Partnering with International and European disability and patient organisations as well as other NGO’s
- Providing information and training on advocacy and policy developments to IF Members

All IF publications are available on the IF website: www.ifglobal.org
How can individuals with SBH and their national associations influence the EU institutions?

The EU and all of its Member States are parties to the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and as such have an obligation to implement the Convention and uphold the rights it bestows. EU policies can have a tremendous impact on the everyday lives of EU citizens. But more than that, everyday citizens can have an impact on EU policies through advocacy on the local and national level.

It is important to remember that the EU institutions are designed to represent the interests of all European citizens and their countries. Each institution has different ways to engage with citizens and civil society.

IF together with its Members will remain actively involved with the European institutions to ensure the strong advocacy for the human rights of the global SBH community.

This can be achieved by:

- Contacting your local MEP
- Getting in touch with the political parties in your region or country which take part in European elections
- Contact your national policy makers, such as ministers
- Raise national awareness and develop advocacy campaigns
- Take part in public consultations organised by the EU institutions
- Become a Member and be active within IF
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