



Inside European Affairs

Hot topics – the revision of the EU Pharmaceutical legislation & Manifesto for the 2024 European elections









The revision of the EU Pharmaceutical legislation

A crucial legislation for children with cancer





What is the current legislative framework?



The General Pharmaceutical Legislation

2001 & 2004

2020



The Orphan Regulation

2000



European Commission
proposed a joint revision
to improve the therapeutic
landscape and address unmet
needs in children



The Paediatric Regulation

2006

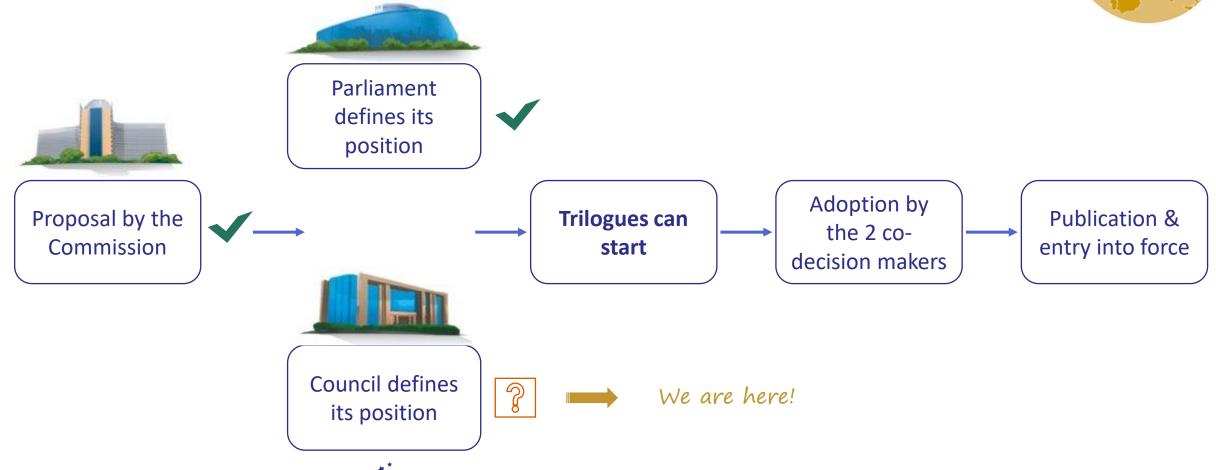
"The revision of the EU Pharmaceutical legislation"





How works the revision of an EU legislation?









What role did CCI-E policy team play?

CCI EUROPE 2024

Revision of the EU
Pharmaceutical legislation

Proposal of the EU
Commission
"the
Pharmaceutical
Package"

Deadline for amendments at the EU

Parliament

Negotiations in Council of the EU

Plenary vote in the **EU Parliament**



April 2023

Nov. 2023

Jan. 2024

April 2024

CCI-E & SIOPE 6 key recommendations cci-E & Siope joint position paper with proposed amendments

CCI-E policy team meetings with Members of the EU Parliament (MEPs)

CCI-E policy team meetings with Health Attachés



Childhood Cancer International EUROPE



At least + 2 years to go

What have we been advocating for?

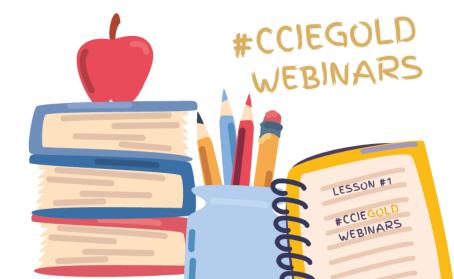
CCI EUROPE 2024

- (1) Unmet medical needs of children
- (2) Mechanism of action
- (3) Early start of Paediatric Investigation Plans
- (4) Repurposing of drugs
- 5 Improved access to essential & anti-cancer drugs
- 6 First-in-Child drugs





Join us to know more about CCI-E & SIOPE priorities next Gold Webinar on JUNE 3!



In conclusion



Current status of the file

Commission's proposal

Parliament's position

Council's position

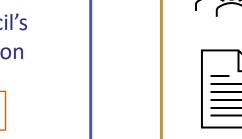
















4 meetings with Health attachés



5 joint positions papers with SIOPE



2 policy events with SIOPE

2 Gold webinars





To find out more, see you on June 3!





Inside European Affairs

Exciting upcoming European Elections – our Manifesto







CCI-E & SIOPE Manifesto for the European elections [2024-2029]



"Cure more, cure better, eradicate inequalities"





Context



- European elections happening from June 6-9, 2024
- CCI Europe and SIOPE have been working on a joint manifesto
- The manifesto was launched at International Childhood Cancer Day event this year
- We count more than 70 signatures from Members of the European Parliament (MEPs) and more than 25 organisations
- We are continuing to approach MEPs and other organisations to ask for political support and commitment
- We are working on translations with the help of national organisations (currently French, Dutch, Croatian, Polish, Bulgarian, Spanish, Portuguese, Italian, Greek...) Let us know if you can help with translation & dissemination!





Content



We advocate **3 priorities** for MEPs:

Saving more lives thanks to better treatments:

more drugs for children and targeting specific

childhood cancers

Childhood cancer constitutes the leading cause of children's death by disease over the age of one in Europe

Supporting the recovery of children and adolescents after their treatment: cancer does not stop after treatment

2/3 of survivors suffer from long term side effects and face other legal and societal challenges

adolescents with cancer: accessible and affordable medicines for all



There is at least a 20% gap in survival rates of young patients among European countries





Content (2)



We focus on 3 axes which are essential to the work of MEPs:



Vote friendly regulations to childhood cancer community

- ✓ Pharmaceutical legislation: Unmet Medical Needs, equal access, academic clinical trials, first-in-child innovation
- ✓ European Health Data Space and other initiatives on data sharing across the EU



Support a generous budget allocated to health and childhood cancer in particular

✓ When negotiating the next Multi-Financial Agreement (2028-2034), maintain prosperous amounts for: Horizon Europe (R&D), EU4Health, Digital Europe



Advocate for our needs during events, in the press and on social media

- ✓ ESCALIER guidelines
- ✓ Psychosocial support





Support our manifesto and spread the word!





- Share it with your network and help spread awareness on our priorities. Let's keep the momentum!
- Reach out to MEPs of your nationality. This
 will help give visibility to the needs of young
 patients and foster the changes that we need
 to improve their survival rates and quality of
 life.





Strategy & Conclusions



1) Strategy

- ➤ We will be **approaching new MEPs** one to one meetings + Gold September event and the **new leadership of the Commission**
- Create an alliance of champions of pro-childhood cancer policies

2) Conclusions

- ➤ Best practices: our collaboration with our members on EU affairs topics has been very helpful use of mother tongue/amplification of contacts & awareness
- ➤ Creating synergies on policy topics: one contact point per member organization is the best scenario. Exchange on EU affairs, share expertise, and help connect people and topics (EU & national level)





THANK YOU for your attention! Any Questions?

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