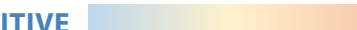



Hæmophilia Care in Europe

Heat Map: Results of the survey of 43 countries

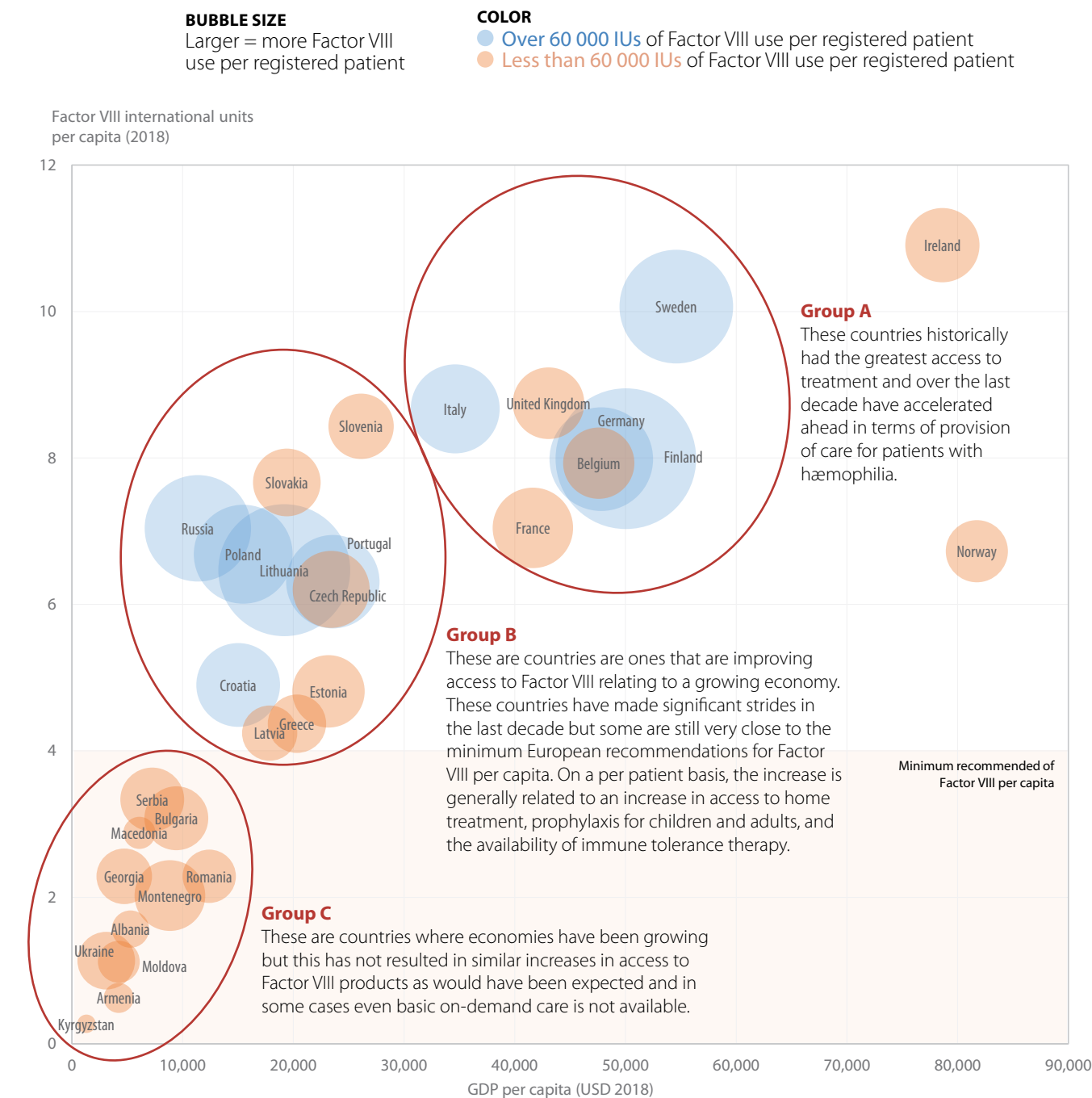
This heat map gives you a quick glimpse into how countries perform when providing care and treatment for haemophilia and other rare bleeding disorders. It reflects the 2018 Survey's results on Comprehensive Haemophilia Care by the European Haemophilia Consortium. **Blue** represent values that either meet or exceed international standards. **Orange** represent values that need to improve while **yellow** show some efforts in the good direction, but that still need work.

Legend																																																				
POSITIVE  NEGATIVE  NO DATA																																																				
Country		Hungary	Ireland	Sweden	Iceland	United Kingdom	Italy	Slovenia	Finland	Germany	Belgium	Slovakia	Switzerland	France	Russia	Norway	Poland	Lithuania	Portugal	Czech Republic	Croatia	Estonia	Greece	Latvia	Belarus	Serbia	Bulgaria	Macedonia	Romania	Georgia	Montenegro	Azerbaijan	Albania	Ukraine	Moldova	Armenia	Kyrgyzstan	Austria	Bosnia and Herzegovina	Denmark	Israel	Netherlands	Spain	Turkey								
International units per capita	Factor VIII	12.63	10.91	10.07	9.90	8.75	8.67	8.43	7.99	7.98	7.93	7.67	7.07	7.05	7.04	6.73	6.69	6.47	6.31	6.21	4.90	4.81	4.37	4.24	<< Above Factor VIII recommendation										>> Below Factor VIII recommendation										No response on Factor VIII >>							
	Factor IX	NR	2.43	2.03	NR	1.22	1.04	0.56	2.20	0.89	0.96	0.58	0.99	0.70	0.76	0.59	0.99	1.28	0.85	0.70	1.30	0.36	0.52	0.37	NR	0.44	0.36	0.48	0.27	0.40	0.29	NR	0.14	0.22	0.06	0.06	0.02	NR	NR	NR	NR	NR	NR	NR								
Organisation of care	Comprehensive Care Centres (CCC's)	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes							
	Haemophilia Treatment Centres	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes						
	National Haemophilia Council or Co-ordinating Group	No	Yes	Yes	No	Yes	No	No	No	No	No	Yes	No	Yes	No	Yes	Yes	No	Yes	Yes	No	No	No	No	No	No	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No	NR	No	No	No	No	No	No	NR	NR	NR	NR	NR					
	Number of groups in decision-making on haemophilia care	2	3	2	2	3	3	2	2	3	3	3	2	3	3	3	3	3	3	3	2	1	3	2	1	3	2	2	2	2	3	2	3	2	NR	2	3	3	1	NR	NR	NR	NR	NR	NR							
	Number of groups choosing haemophilia treatment products	2	3	2	2	3	3	2	2	2	3	3	3	1	3	3	3	2	3	3	2	2	1	1	1	2	2	2	2	2	3	2	2	3	NR	2	2	1	NR	NR	NR	NR	NR	NR								
	National Tender for procurement of factor concentrates	Yes	Yes	No	Yes	Yes	No	Yes	No	No	No	No	Yes	No	No	Yes	Yes	Yes	No	Yes	No	No	Yes	No	No	No	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes	NR	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes					
Treatment regimens	Home Treatment	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NR	No	No	No	No	No	No	No	No	No	No	No	No					
	% of people with haemophilia using home treatment	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	51-75%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	10-50%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%					
	Treatment delivered to the patient's home	No	Unknown	Some	No	Unknown	Some	No	Some	Some	Some	No	Unknown	Some	Some	Unknown	Some	Some	No	No	Some	Some	Unknown	No	No	No	No	No	No	No	No	Some	Unknown	No	NR	No	No	No	No	No	No	No	No	No	No	No	No					
	Prophylaxis treatment availability	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Some	Yes	Yes	Yes	Yes	Yes	Yes	Children	Children	Some	Some	Yes	Children	No	Some	No	Some	No	Some	No	Some	No	Some	No	Some						
	Children currently on prophylaxis (%)	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	51-75%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%					
	Adults currently on prophylaxis (%)	51-75%	76-100%	76-100%	76-100%	76-100%	76-100%	51-75%	51-75%	51-75%	76-100%	51-75%	76-100%	51-75%	51-75%	76-100%	76-100%	51-75%	51-75%	51-75%	26-50%	26-50%	26-50%	26-50%	76-99%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%	76-100%				
Access to ITI (% of people with inhibitors)	76-99%	100%	100%	100%	100%	76-99%	100%	100%	100%	100%	100%	100%	100%	100%	76-99%	100%	100%	1-25%	76-99%	100%	1-25%	100%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%	76-99%				
Access to specialist services	Emergency medicine and acute surgery	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	NR	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes				
	Paediatrics	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes				
	Infectious disease specialists (especially HIV)	Sometimes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes	Sometimes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	NR	Yes	Sometimes	NR	Yes	Sometimes	NR	Yes	Sometimes	NR	Yes	Sometimes	NR	Yes	Sometimes			
	Hepatology	Sometimes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes	Sometimes	Yes	Yes	Sometimes	Yes	Sometimes	Yes	Never	Sometimes	Yes	Yes	NR	Yes	Sometimes	NR	Yes	Sometimes	NR	Yes	Sometimes	NR	Yes	Sometimes	NR	Yes	Sometimes			
	Rheumatology	Never	Yes	Sometimes	Yes	Yes	Sometimes	Never	Yes	Yes	Yes	Yes	Sometimes	Yes	Never	Yes	Yes	Yes	Yes	Yes	Yes	NR	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Never	Yes	Never	Yes	Never	Never	NR	Sometimes	Sometimes	NR	Sometimes	Sometimes	NR	Yes	Sometimes	NR	Yes	Sometimes	NR					
	Orthopaedics	Sometimes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	NR	Yes	Yes	NR	Yes	Yes	NR	Yes	Yes	NR	Yes	Yes	NR					
	Physiotherapy	Sometimes	Yes	Yes	Sometimes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Sometimes	Yes	Sometimes	Yes	NR	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	NR	Yes	Sometimes	NR	Yes	Sometimes	NR	Yes	Sometimes	NR	Yes	Sometimes					
	Dentistry	Never	Yes	Yes	Never	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Sometimes	Sometimes	Sometimes	Sometimes	Sometimes	Yes	Yes	Yes	Yes	Yes	Never	Sometimes	Yes	NR	Yes	Sometimes	NR	Yes	Sometimes	NR	Yes	Sometimes	NR	Yes	Sometimes						
	Obstetrics and Gynaecology	Never	Yes	Yes	Never	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Sometimes	Yes	Sometimes	Never	Yes	Yes	Yes	Yes	NR	Yes	Sometimes	Sometimes	Sometimes	Sometimes	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	NR	Yes	Sometimes	NR	Yes	Sometimes	NR	Yes	Sometimes	NR	Yes	Sometimes	NR						
	Genetics	Never	Yes	Yes																																																

Significant disparity of access across Europe

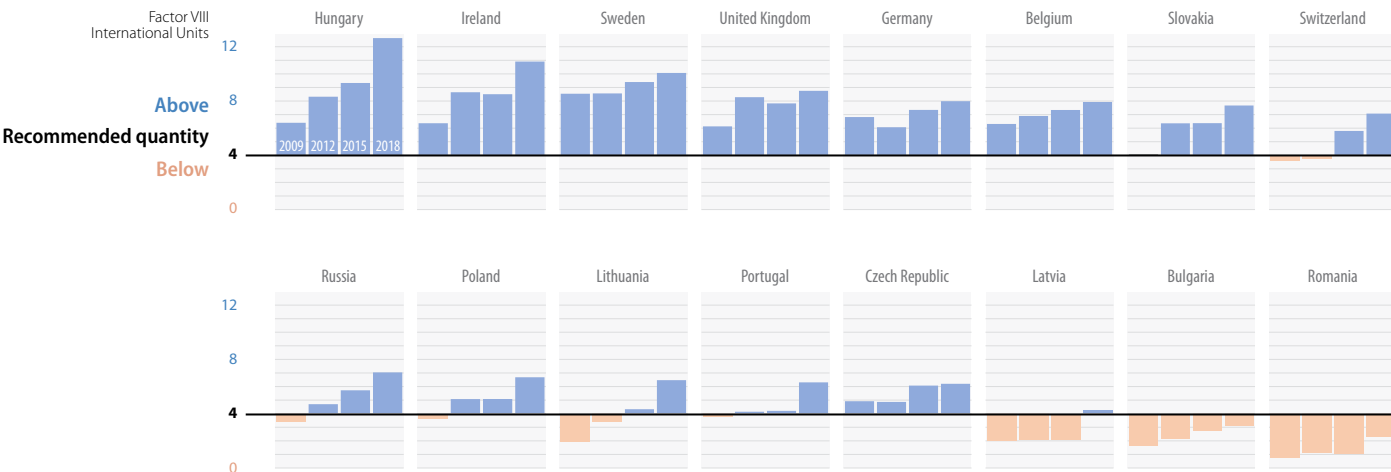
The graph below summarizes the use of Factor VIII per capita compared to GDP per capita for each country that provided data for 2018. The graph highlights the significant difference in the amount of Factor VIII available in a country and compares this to GDP, which is used as indication of ability to pay. The size of the circles for each country represent the Factor VIII use based on reported registered patients. This is used to identify the access by those patients with haemophilia within each country to treatment and begin to understand the impact of a registry.

Overall, there is a clear disparity across Europe with three distinct groups developing. In the coming years there should be an emphasis on growing the Factor VIII per capita, Factor VIII per patient and the optimisation of Factor VIII use through registries to ensure equity across Europe for all patients. The disparity already present in the three groups should not increase.



A positive trend in meeting EDQM Factor VIII recommendation

For countries that have reported in all four surveys, there is a positive trend in terms of access to Factor VIII products represented by Factor VIII per capita. Whilst all countries have increased the overall volumes, there are still some countries that remain below the minimum recommended European standards after 10 years of improvement.



EHC Headquarters
Rue de la loi 28
Brussels, 1000 Belgium
www.ehc.eu | office@ehc.eu

2021 EDITION

HÆMOPHILIA CARE IN EUROPE

Survey of 43 countries



Europe is a disparate continent with a wide range of economic conditions and health systems in individual countries. In 2008, the *European principles of haemophilia care* were drafted by an interdisciplinary group of haemophilia physicians with input from key patient opinion leaders and endorsed by EHC and EAHAD.

These principles are:

1. Establishment of a central haemophilia organisation in each country with supporting local group
2. National haemophilia patient registries
3. A network of multidisciplinary comprehensive care centres and complementary haemophilia treatment centres
4. Partnership of health care professionals and patients in the delivery of haemophilia care
5. Safe and effective concentrates at optimum treatment levels
6. Home treatment and delivery
7. Prophylaxis
8. Specialist services and emergency care
9. Management of inhibitors
10. Encouragement of education and research

In 2009, the EHC carried out a survey in order to determine the extent to which haemophilia care in across the continent of Europe compared with these principles. A total of 19 countries responded to the first survey¹. This survey identified significant gaps in terms of the provision of care in haemophilia within each country. The survey was repeated in 2012² with 35 countries responding and again in 2015³ with 37 countries. Over these six years, with the significant increase in countries reporting a clearer picture of these disparities emerging. Whilst there have been increases in the availability of clotting factor concentrates (CFC), there are still 13 countries who remain below the EDQM minimum recommendations for CFC4, with further 5 countries unable to provide data on CFC use due to lack of access to data.

The picture developing shows that countries with a highly organised system for delivering haemophilia care is capable of producing a level of care beyond their economic constraints. These are countries with good registries that record all people with haemophilia (mild, moderate, severe), have patient and clinician involvement in all aspects of care including decision-making on haemophilia care and choosing haemophilia treatment products. These countries also include a well-defined network of comprehensive care centres and haemophilia treatment centres to treat patients effectively and optimise the use of CFC's to maximise the benefits for patients.

¹ O'Mahony B, Noone D, Giangrande PLF, Prihodova L. Haemophilia care in Europe: A survey of 19 countries. *Haemophilia*. 2011;17(1):35-40. doi:10.1111/j.1365-2516.2010.02362.x.
² O'Mahony B, Noone D, Giangrande PLF, Prihodova L. Haemophilia care in Europe - a survey of 35 countries. *Haemophilia*. 2013;19(4). doi:10.1111/hae.12125.
³ O'Mahony B, Savini L, Hara JO, Bok A. Haemophilia care in Europe - A survey of 37 countries. *Haemophilia*. 2017;23(4):e259-e266. doi:10.1111/hae.13263.
⁴ Giangrande PLF, Peyvandi F, O'Mahony B, et al. Kreuth IV: European consensus proposals for treatment of haemophilia with coagulation factor concentrates. *Haemophilia*. 2017;23(3):370-375. doi:10.1111/hae.13211.

Respondent countries for each survey

Country	2009	2012	2015	2018
Belgium	•	•	•	•
Bulgaria	•	•	•	•
Czech Republic	•	•	•	•
Germany	•	•	•	•
Hungary	•	•	•	•
Ireland	•	•	•	•
Latvia	•	•	•	•
Lithuania	•	•	•	•
Netherlands	•	•	•	•
Poland	•	•	•	•
Portugal	•	•	•	•
Romania	•	•	•	•
Russia	•	•	•	•
Slovakia	•	•	•	•
Sweden	•	•	•	•
Switzerland	•	•	•	•
United Kingdom	•	•	•	•
Albania		•	•	•
Armenia		•	•	•
Austria		•	•	•
Azerbaijan		•	•	•
Bosnia and Herzegovina	•	•	•	•
Denmark		•	•	•
Finland		•	•	•
France	•	•	•	•
Greece		•	•	•
Italy		•	•	•
Macedonia		•	•	•
Norway		•	•	•
Serbia		•	•	•
Slovenia		•	•	•
Spain		•	•	•
Turkey		•	•	•
Ukraine		•	•	•
Croatia		•	•	•
Estonia		•	•	•
Georgia		•	•	•
Israel		•	•	•
Kyrgyzstan		•	•	•
Montenegro		•	•	•
Belarus			•	•
Iceland			•	•
Moldova			•	•