

# The European Registries for Rare Endocrine and Bone conditions (EuRREB): Results from the Platform for e-Reporting of Rare Conditions (e-REC)

For more details, check the annual report at [eurreb.eu](http://eurreb.eu)



## Introduction

The European Registries for Rare Endocrine and Bone conditions (EuRREB) was created in collaboration with the European Reference Network on Rare Endocrine Conditions (Endo-ERN) and the European Reference Network on Rare Bone Diseases (ERN BOND) to support the needs of healthcare providers, patients and researchers by providing high-quality registries.

## Aim

To describe the centres activity and data entered in the e-REC Registry between July 2018 and December 2024.

## Methods

The e-REC platform issued invitations to clinicians who had registered to participate in e-REC to complete a monthly return. Participants can create a bespoke reporting set up and report any newly encountered cases of any of the conditions that have been included in Endo-ERN and ERN-BOND.

## Results

By December 2024, 113 centres from 32 countries had reported on the e-REC a total of 56573 new cases. Of these 113 centres, 62 are in Endo-ERN only, 29 are in Endo-ERN and ERN-BOND, three are in ERN-BOND only and 19 are not related to ERNs. Since January 2024, two new countries and 12 new centres have joined the platform.

Since 2018, three important events have prompted the increase in e-REC participation: the launch of the EuRR-Bone project (April 2020), mandatory participation of Endo-ERN members in 2023 and of ERN BOND members in 2024 (Figure 2). A total of 41933 new cases in adults and 14640 new cases in children have now been reported, with a growing trend in both groups. Conditions within the 'Sex Development', 'Growth & Obesity' and 'Thyroid' condition groups were most commonly reported in children, whereas in adults the most reported were conditions within the 'Hypothalamic and Pituitary', 'Thyroid' and 'Adrenal' groups (figure 3).

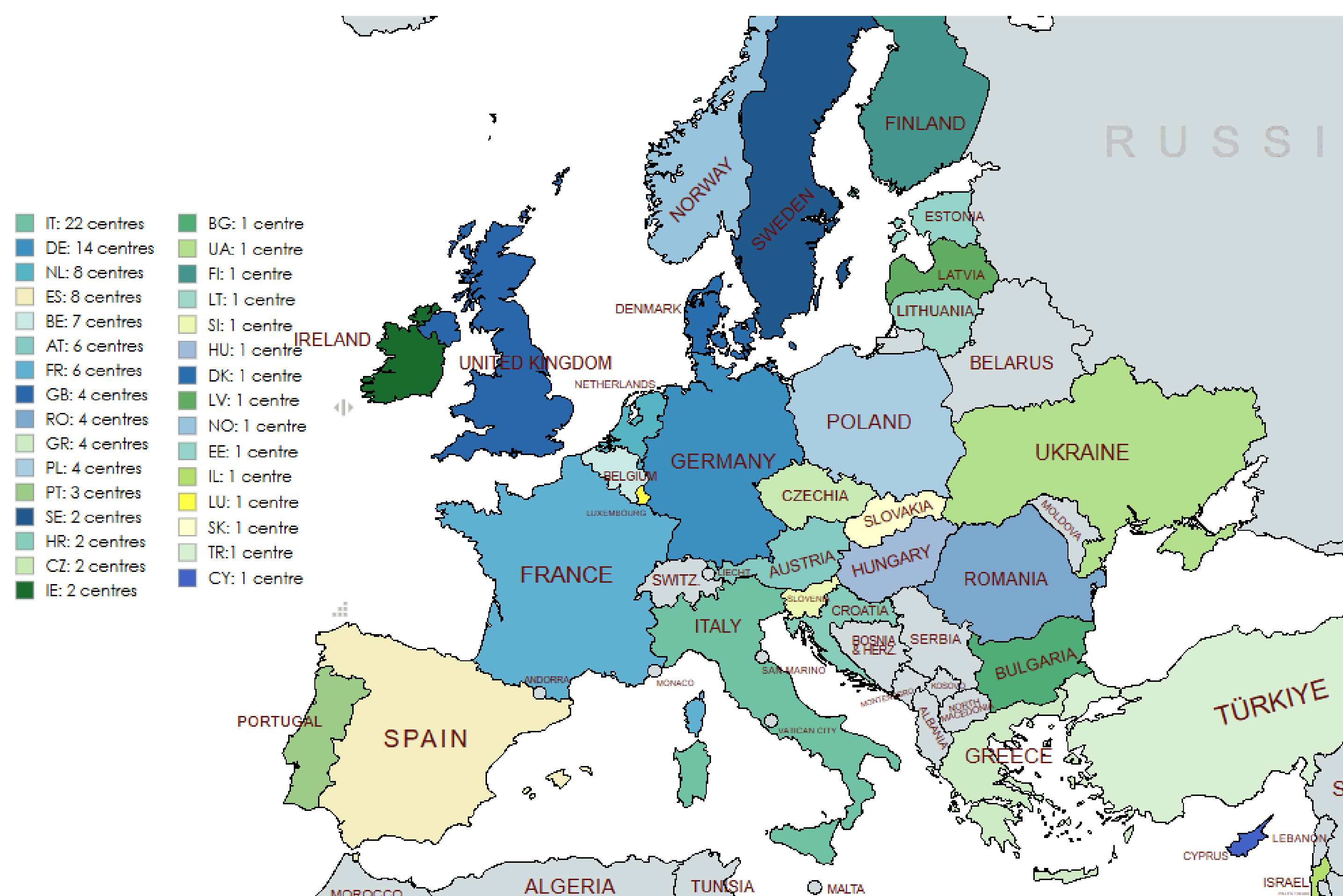


Fig. 1 – Reporting countries and centres in the e-REC

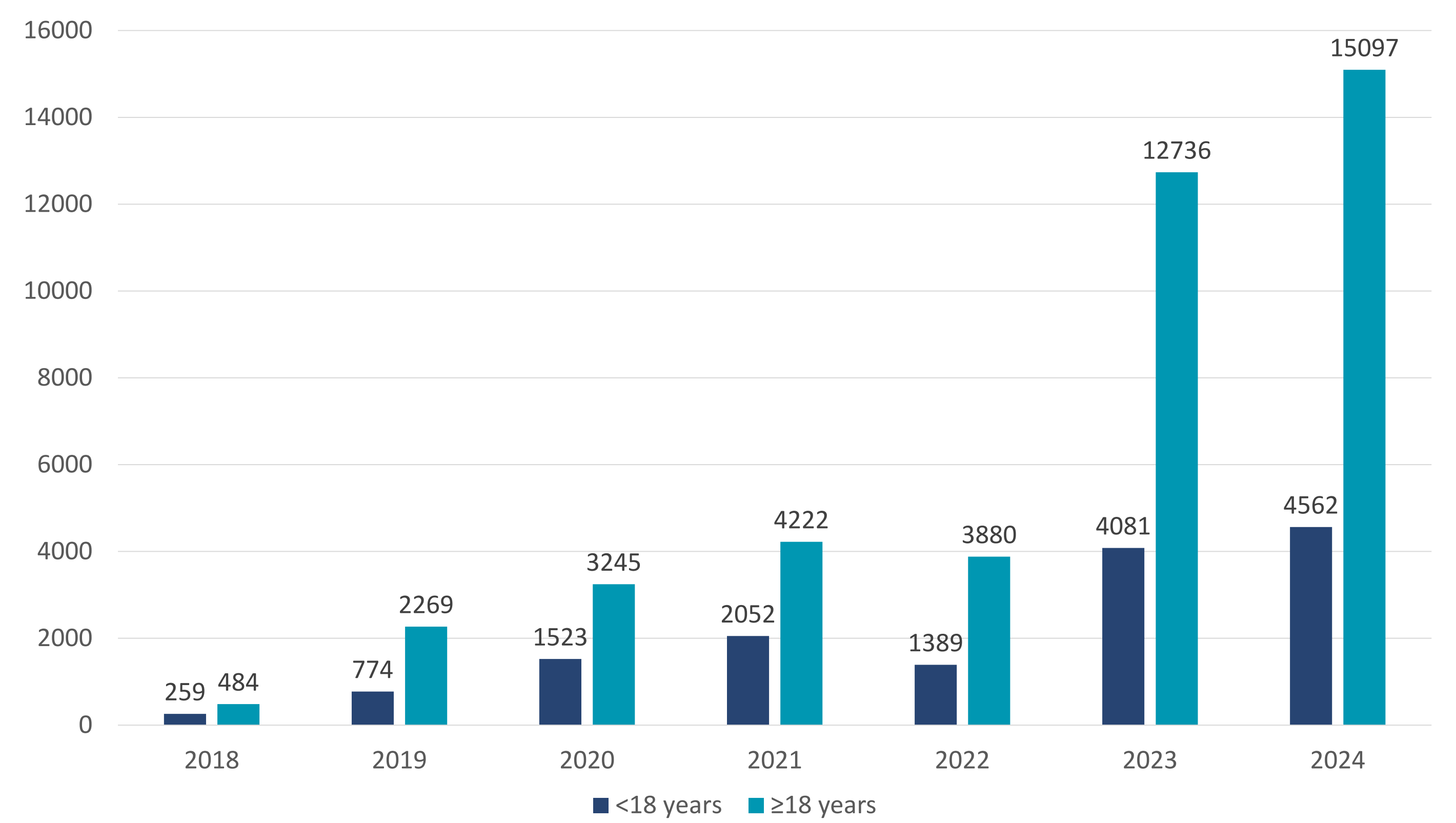


Fig. 2 – The trends in reported cases between July 2018 and December 2024

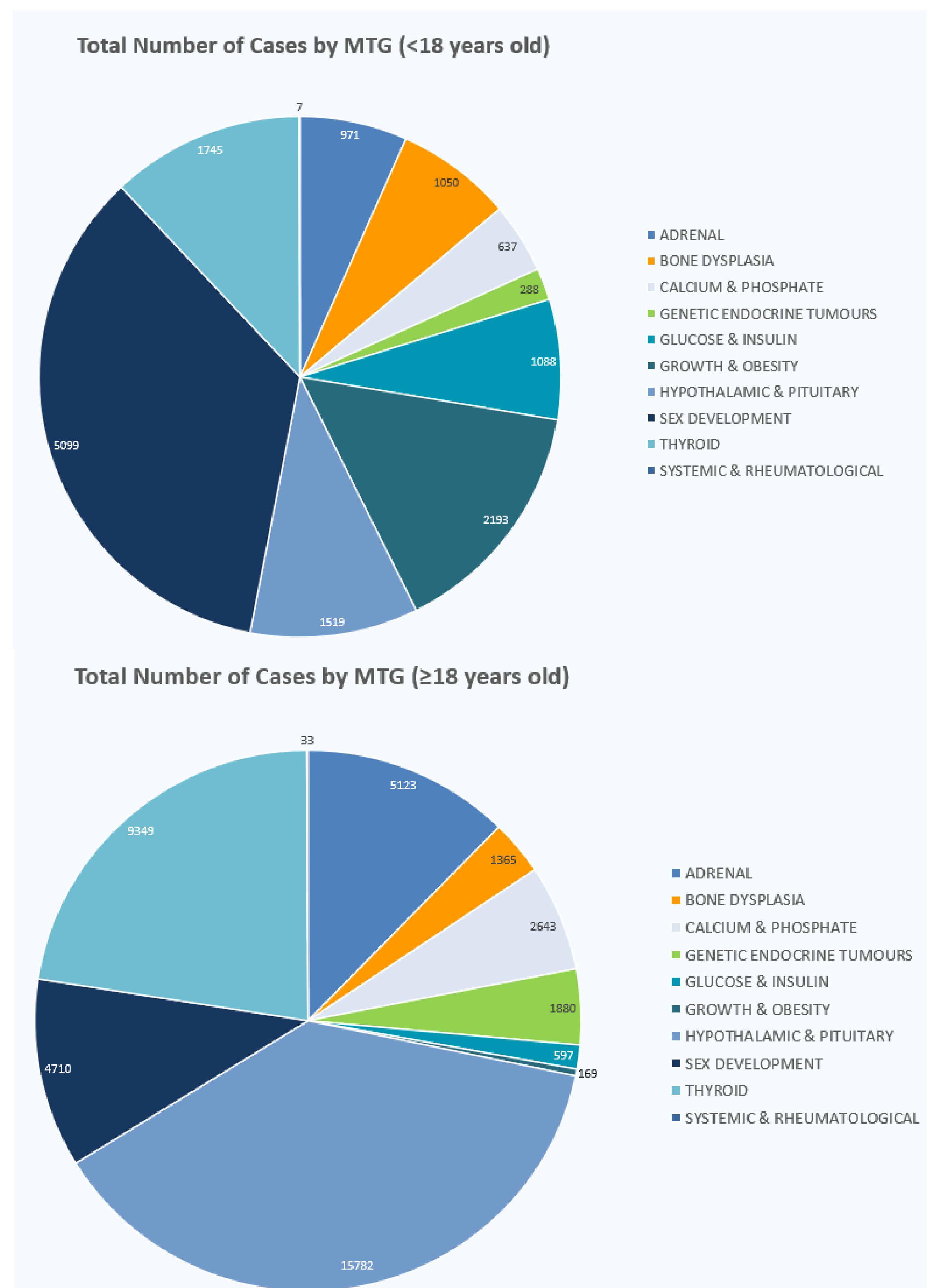


Fig. 3 – Cases reported per Main Thematic Group (MTG) between July 2018 and December 2024 in children and adults

## Conclusion

The number of registered centres in the platform and of those actively reporting cases continues to increase. The continuous monitoring program of Endo-ERN and ERN BOND were important drivers of this growth during the last years. There is wide variability in the number of cases encountered for different conditions across different centres. The biggest number of centres reported in MTG 6. To date, this provides a large dataset which is available for researchers upon request.