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| Freedom of Information Request | FOI 23-350 | 11 August 2023 |
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Your request

You requested the following:

This person wished to raise awareness of people living in Wales with the rare condition, X-linked hypophosphataemia (XLH). They spoke about how one of the most critical factors to improve the care pathway for people who have XLH, will be determined by the way in which Local Health Boards implement the Rare Disease Action Plan for Wales 2022-26 into their operational and financial planning systems.

They noted that when the Rare Disease Action Plan for Wales 2022-26 was published last summer, the Welsh Health Circular that accompanied the Plan (WHC-2022-017), set out clear expectations for Health Boards to facilitate and implement the priorities and actions in the Plan over its lifetime.

Welsh Health Circular have said “Health boards should take account of the priorities for rare diseases when planning their services and developing their Integrated Medium-Term Plans (IMTPs)”. Given that the Action Plan is still in its first year of implementation, it is extremely important that the Health Board embeds the Plan’s four key priorities, both in financial and operational terms, into their IMTPs.

They have requested for you to provide an update on the following questions:

1. How is the Health Board is implementing the Rare Disease Action Plan for Wales and what progress has been made on the four priorities to date, including identifying actions, delivery partners, timelines and outcome measures?
2. How many patients with X-linked hypophosphataemia (XLH) is the Health Board currently treating?
3. For those patients with XLH, how is the Health Board improving care coordination, as well as access to specialist care, treatment and medicines?

Our response

We have previously responded this request and our response is available to view on our Freedom of Information (FOI) Disclosure Log. The link to the disclosure has been provided below.

FOI 23-264

<https://abuhb.nhs.wales/files/freedom-of-information/june-2023/foi-23-264-rare-disease-action-plan-for-wales-and-patients-with-x-linked-hypophosphataemia-xlh-pdf/>