



Children's Health Ireland

Sláinte Leanaí Éireann (SLÉ), Herberton, Siúlán San Séamas, Rialto, D08 HP97, Éire  
Children's Health Ireland (CHI), Herberton, St James's Walk, Rialto, D08 HP97 Ireland

Our Ref: PQ 24039/22

25<sup>th</sup> May 2022

**Deputy Sorca Clarke**  
**Dáil Eireann**  
**Dublin 2**

Dear Deputy Clarke

I refer to your recent PQ which has been forwarded to me for attention.

**PQ: To ask the Minister for Health the way a child with a diagnosis of Atraxia Telangiectasia can access clinical trials outside of Ireland.**

**Childrens Health Ireland (CHI) Response:**

I have followed up with Children's Health Ireland (CHI) and can advise that there isn't a formal referral process for the way a child with a diagnosis of Atraxia Telangiectasia can access clinical trials outside of Ireland as every trial is different and every subject has unique attributes that may make them suitable or unsuitable.

Children's Health Ireland Clinical Research Centre (CRC) is a Health Research Board (HRB) funded CRC that is responsible for the operation of clinical trials across CHI. We are actively trying to increase the number of clinical trials available to children in Ireland in partnership with our colleagues around Ireland. People do travel internationally for clinical trials when not available locally but this relates mostly to the willingness of the trial site to accept them, rather than the willingness to travel.

The usual process is that a parent will discuss with their child's doctor whether a particular trial would be suitable for their child or not. This would then be followed by a request to the international site to determine whether the site has capacity to take the child on. If this is feasible then a plan will usually be put in place between the referring and receiving sites and the parents to ensure that all of the medical needs of the child can be safely met during the conduct of the trial. By necessity this whole process is very bespoke.

I trust this is of assistance to you.



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Yours sincerely

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**Chief Operations Officer**

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Our **Mission** is to: Promote and provide child-centred, research-led and learning informed healthcare, to the highest standards of safety and excellence. We will do this in partnership with each other, with children, young people and their families through a network of children's services in Ireland.  
CRA Registered Charity Number (RCN): 20202295 Revenue Charitable Status CHY: 22235  
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