How Alex TLC Supports Research



Research Summaries and Updates

Every month we provide summaries of the most recent research and updates from pharmaceutical companies in a format that can be easily understood. This allows our community members to stay updated on interesting articles and progress made in the research community.

Pharmaceutical and research professionals also benefit from our monthly research summaries and updates. It saves them time and effort by providing information in a condensed form.

Patient Voice for New Research



As the recognized voice for leukodystrophy patients in the UK, Alex TLC provides information and guidance to researchers which ensures new initiatives keep patient priorities firmly at the forefront of research development.



Collaboration

Alex TLC is the lead patient voice representative for the NHS England Inherited White Matter Disorder Service and Patient Registry. We are also partnered with Leukolabs, a group of UK leukodystrophy researchers. These key partnerships, alongside our extensive global stakeholder network, give us optimal opportunities to be significantly involved in research development.

Access to Patient Data



Alex TLC regularly collects a wealth of data and feedback from our leukodystrophy community through the Alex TLC database, regular surveys and focus groups. This data is shared with stakeholders via our Impact Reports, commissioned research, and upon request. It is also used as the basis for Alex TLC campaigns, NICE, NHS and National Screening Committee consultations.

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