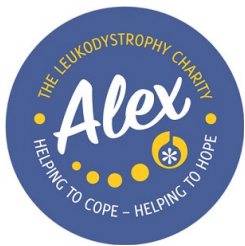


BRIDGING THE GAP BETWEEN THE RESEARCH COMMUNITY AND THE ALEX TLC PATIENT AND CARER COMMUNITY

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alextlc.org

AIMS

At Alex TLC, we strive to connect the research community with our patient and carer network through clear and accessible research communications. Our goal is to make recent updates easy to understand and demonstrate how they can benefit patients.

METHODS

- Dedicated Research Analyst funded by the National Lottery
- Plain English training undertaken by the Alex TLC team
- Research volunteers recruited through our stakeholder network
- Collection and selection of the latest and most impactful peer-reviewed leukodystrophy research from trusted scientific journals, with key updates from pharmaceutical companies
- Monthly publication, available via our website and research newsletter

RESULTS

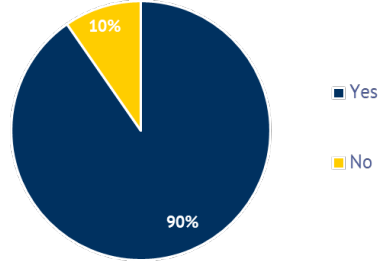
90% of respondents reported finding the research summaries beneficial for understanding current research:

- *“The research summaries show that hope exists for my condition.”*
- *“...useful to keep up with current research [as] it would be difficult for me to find the information myself.”* (Alex TLC Charity Impact Report 2024)

INCIDENTAL FINDING: Leukodystrophy professionals found the summaries informative, concise, and time-saving:

- *“The research summaries provide a useful, well-curated summary that helps keep me informed about the latest developments in the field, saving me the time of sifting through countless publications.”* (Alex TLC Community Weekend Impact Report 2024)

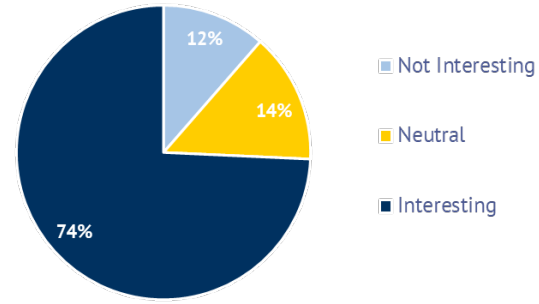
Do you find our research summaries beneficial to you and your understanding of the current leukodystrophy research?
Source: Alex TLC Charity Impact Report 2024



BACKGROUND

Leukodystrophies are rare genetic disorders affecting the white matter of the central nervous system, including the brain and spinal cord. Due to their rarity, lack of effective treatments and terminal prognosis, any new information is invaluable to the leukodystrophy community. Previous Alex TLC impact reports have shown how crucial it is for our community to stay informed about research updates, in 2022, 74% of respondents were interested in research and treatment information in Alex TLC communications.

Interest in research and treatment information in Alex TLC communications
Source: Alex TLC Charity Impact Report 2022



DISCUSSION AND CONCLUSION

Plain English research summaries help patients and families understand complex scientific findings and empower leukodystrophy patients to make informed decisions. These summaries also assist medical professionals in improving communication and care. Balancing simplicity with scientific accuracy has been key to our success, and the process we have developed can be easily replicated to benefit other communities. By making research more accessible, we ensure that important information reaches those who need it most.