Spot the stop: A multi-channel campaign to improve early diagnosis of Tay-Sachs disease among healthcare professionals

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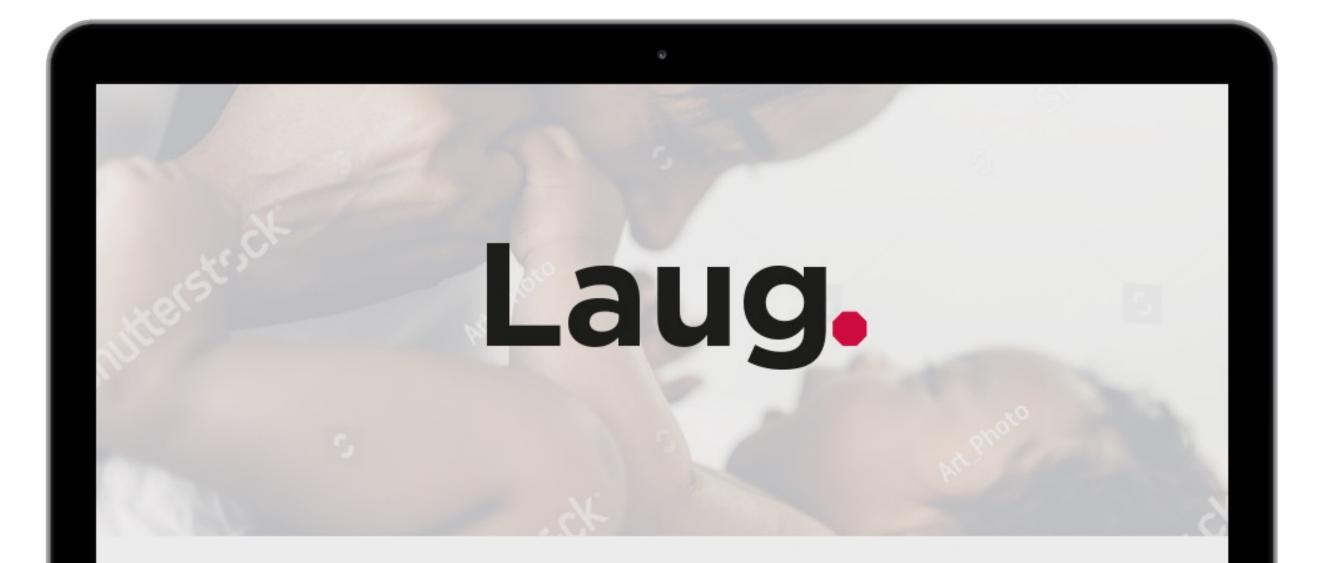
INTRODUCTION

Tay-Sachs is a neurodegenerative disease primarily affecting infants, marked by the progressive loss of motor and cognitive functions. Early diagnosis is crucial, as it enables timely initiation of supportive care, participation trials, and informed decision-making for families. Despite the

RESULTS

As part of the campaign, a dedicated microsite (<u>www.test-</u> for-tay-sachs.com) served as the central hub, offering information on diagnostic procedures and access to educational materials to support early diagnosis.

importance of early detection, awareness among health care professionals (HCPs) remains limited, resulting in delayed diagnoses and missed opportunities for intervention. In some cases, diagnosis can take over 12 months and in this time the disease can progress significantly where any potential treatments would be ineffective.



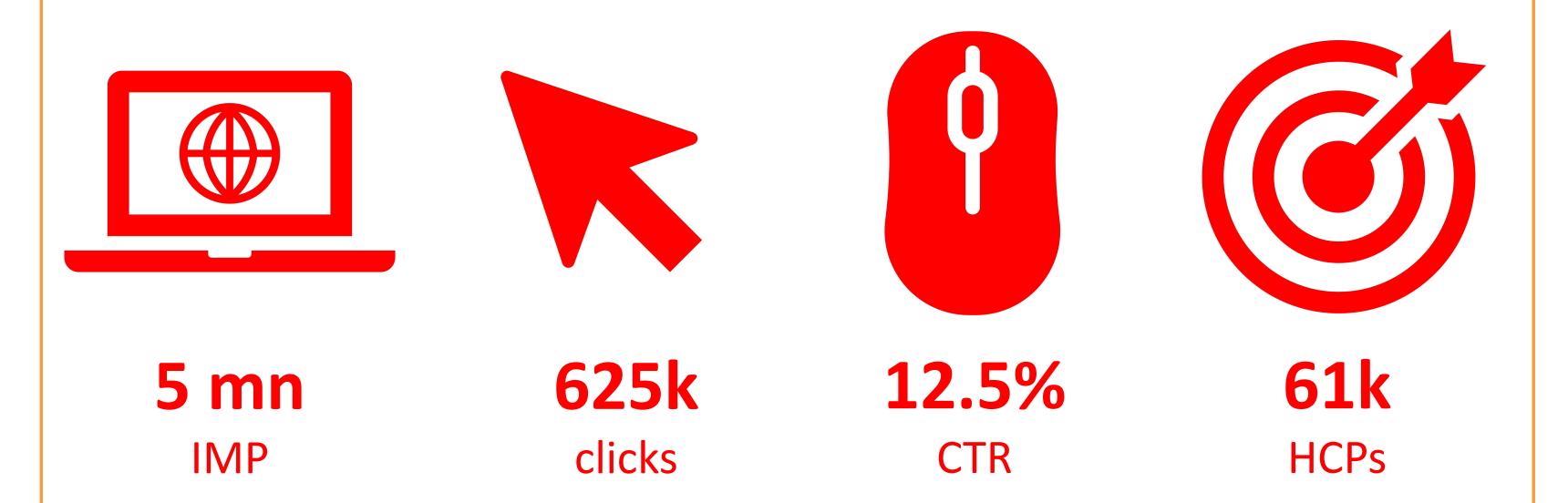
When development stops. Test for Tay-Sachs.

When an infant or child suddenly stops being able to do the things that come naturally, the stress and worry of the 'wait and see' approach can put enormous burden on family dynamics and potential rob them of precious time.

You can help ease their minds by doing a simple blood or Macular Cherry-Red Spot test at the first sign of any

MacBook

developmental issues and be able to rule out anything sinister like Tay-Sachs, a terminal rare disease



In the first three months, the campaign generated 5 million impressions (IMP) and over 625,000 clicks, with a clickthrough rate (CTR) of 12.5%, significantly surpassing industry benchmarks.



OBJECTIVES & METHODS

To address this, The CATS Foundation, in collaboration with Verve and Four Agency, launched the pro-bono "Spot the Stop" campaign. This initiative aimed to enhance disease recognition and promote early diagnostic practices.

The "Spot the Stop" campaign demonstrates the critical role of targeted education in improving early diagnosis for rare diseases like Tay-Sachs. By creatively highlighting subtle developmental symptoms and using a strategic multi-channel approach, the campaign engaged over 61,000 healthcare professionals, leading to three confirmed diagnoses and a significant increase in awareness. Early diagnosis of Tay-Sachs is vital as it enables timely intervention, better management, and access to emerging therapies, ultimately improving patient outcomes and quality of life. These results underscore the importance of collaborative efforts between advocacy groups, healthcare organizations, and creative agencies in addressing the diagnostic challenges faced by rare disease communities. The campaign's success shows how innovative initiatives can bridge critical gaps in healthcare knowledge, ensuring that subtle disease markers are recognized and acted upon promptly. Future efforts should build on this success by scaling the approach to other regions and conditions, incorporating advanced digital tools to further enhance outreach and engagement. Campaigns like "Spot the Stop" serve as a model for addressing the complexities of rare disease diagnostics, setting a new standard for proactive, impactful advocacy.

The campaign targeted over 61,000 HCPs through a strategically designed, multi-channel approach. The campaign's strategy involved educating HCPs on the early, often subtle, symptoms of Tay-Sachs, such as a halt in previously acquired developmental skills including "laughing," "crawling," and "speaking." These symptoms were creatively highlighted using STOP sign iconography to signify the critical 'stops' in development that warrant further investigation, including searching for the presence of a cherry-red spot which is a well-documented clinical feature of Tay-Sachs and when identified can lead to a quick diagnosis.



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