

# MacularNEWS

Autumn 2025 : Edition

## Finally, an Effective Treatment for Adults with MacTel

*The FDA approves the Encapsulated Cell Therapy  
Delivering Ciliary Neurotrophic implant (ENCELTO™)*

Macular Telangiectasia type 2 (MacTel) is a rare and progressive eye disease that affects the macula—the central part of the retina responsible for sharp, detailed vision. Although relatively unknown to many, MacTel (Macular Telangiectasia) is actually quite a common ocular condition (up to 1:1000 people) that can significantly affect a person's ability to read, drive, recognise faces and perform everyday tasks. The Macular Research Group is proud to have played a pivotal role in the dedicated research over the last 20 years that has expanded our understanding of this complex condition.

### What Is MacTel?

MacTel is a degenerative retinal disease that typically affects both eyes, often developing in midlife. Its exact cause remains under investigation, but research suggests that genetic factors and metabolic changes in the retina contribute to its onset. MacTel is like age-related macular degeneration (AMD) but starts earlier and progresses more subtly, making early diagnosis challenging. Patients often notice a gradual loss of central vision, which can affect their quality of life.



### Director's Message

In this edition of MacularNEWS, we highlight the pivotal role played by the Macula Research Group in the international MacTel scientific collaboration, along with the exciting news of the newly approved ENCELTO™ implant.

Thank you for your continued interest in our work. I hope you enjoy reading this edition.

**Professor Mark Gillies**  
Macula Research Group



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## **The MacTel Project: A Global Collaboration**

The MacTel Project is an international research initiative aimed at unravelling the mysteries of this disease, developing diagnostic tools and exploring potential treatments. Spearheaded by the Lowy Medical Research Institute (LMRI), the project brings together leading scientists, ophthalmologists and researchers from around the world. Its collaborative approach is essential for studying a poorly understood disease like MacTel, as pooling data and expertise accelerates progress.

## **Our Role in the MacTel Project**

At the Macular Research Group, based within the Save Sight Institute, we are honoured to have contributed to the MacTel Project through our expertise in clinical and laboratory research, data collection and patient care. Mark Gillies helped establish the international collaboration as Chair of the Scientific Advisory board for the first 8 years of the project. Our involvement has focused on several key areas:

- **Clinical Trials and Patient Care:** We participate in clinical trials that assess potential treatments. By working directly with patients, we gather critical data that helps researchers understand how MacTel progresses and how different therapies might slow or halt its effects. The Macula Research Group's Clinical Trials Unit was the top patient-enrolling centre of 32 clinics world-wide in the randomised clinical trials that established that the ciliary neurotrophic factor implant delayed loss of vision in people with MacTel.
- **Laboratory Research:** the Macula Research Group's lab identified the first human sample of MacTel, which suggested that the condition was characterised by loss of supporting cells in the retina that kept photoreceptors alive. This allowed the project to identify that a neuroprotectant might be effective in delaying the loss of photoreceptors that causes loss of vision in MacTel. More recently, we have pioneered the use of explants of human maculas in test tubes that allow us to understand better the metabolic abnormalities that lead to MacTel (reported in our last newsletter, Spring 2024)
- **Collaboration and Knowledge Sharing:** Our team works closely with international partners, sharing insights and collaborating on studies that advance the global understanding of MacTel. This collaborative spirit ensures that breakthroughs in one region can benefit patients worldwide.

## **Milestones and Achievements**

Recent years have seen significant progress in MacTel research. Advances in imaging technology, such as optical coherence tomography (OCT) and adaptive optics, have improved our ability to detect early signs and measure reduced topographical function of the disease. Genetic studies have identified key risk factors, paving the way for potential gene-based therapies.

A major milestone was recently achieved when the US Food and Drug Administration approved the ciliary neurotrophic factor implant, ENCELTO™, for the treatment of adults with MacTel, which previously had no effective treatments (<https://www.neurotechpharmaceuticals.com/neurotechs-enceltotm-revakinagene-taroretcel-lwey-approved-by-the-fda-for-the-treatment-of-macular-telangiectasia-type-2-mactel/>).

The implant does not restore vision in people with MacTel, nor does it completely prevent loss of vision. But it does significantly delay loss of vision. For example, if someone were to lose their driving vision in 5 years, it might delay that for another 5 years.

This is the amazing result of an international collaboration that started 20 years ago when we did not even know what type of disease MacTel was – we thought it was mainly driven by disease of the retinal blood vessels, but it turned out to be something quite different. This advance is also a breakthrough in using encapsulated cells to deliver a drug. Other drugs to treat retinal diseases must be injected repeatedly, sometimes every 6 weeks, whereas the Encelto® implant may deliver drug for up to 15 years after it has been inserted.

## **Looking Ahead: The Future of MacTel Research**

While much progress has been made, the journey to fully understand and treat MacTel is ongoing. The next phase of research will focus on developing therapies that can halt or even reverse vision loss. Gene therapy, neuroprotection and regenerative medicine are all promising avenues that researchers are actively exploring.

It is envisaged that the ENCELTO™ implant will become available in the United States in around June this year. It would likely be available to Australian patients through the Therapeutic Goods Administration's Special Access Scheme, but patients would have to pay themselves. We will be pushing for the company, Neurotech, to register the device in Australia and then we will push for it to be reimbursed by the government for our patients. Unfortunately, this process might take a year or two.

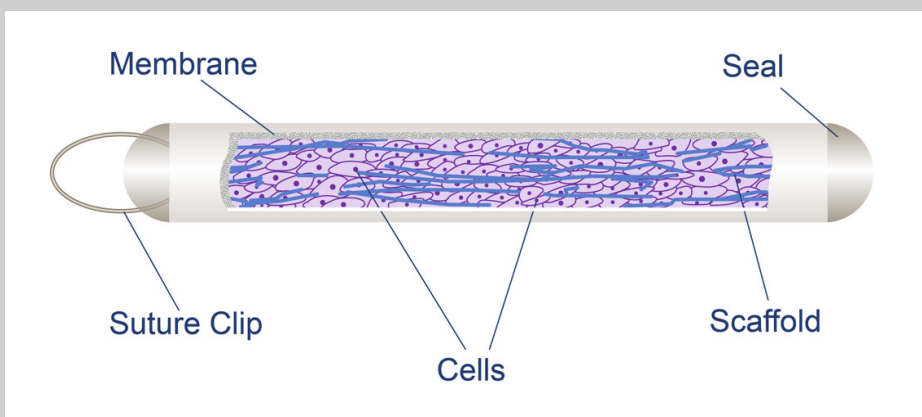
## Thank You for Your Support and Participation

The achievements of the MacTel Project—and our role within it—would not be possible without the support and participation of our patients, collaborators and donors. Your generosity enables us to conduct groundbreaking research, provide compassionate care, and bring hope to those affected by MacTel. Together, we are making a difference in the lives of individuals around the world.

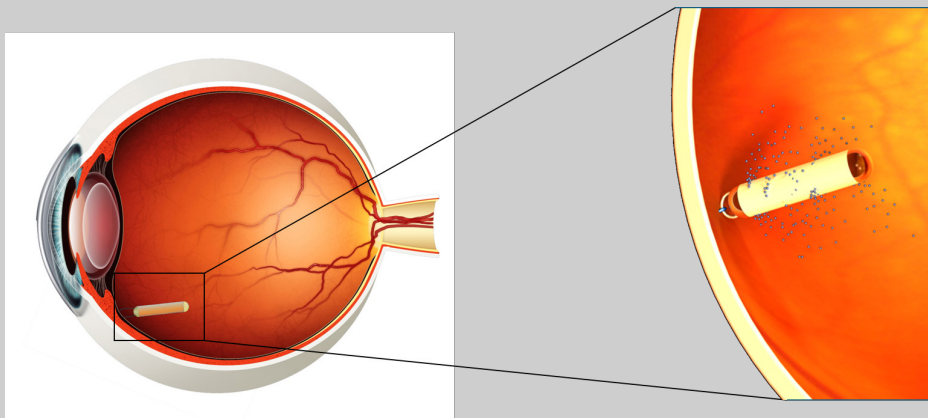
If you would like to learn more about the MacTel Project or support our research, please visit our website or LMRI.net. Thank you for being part of our mission to fight retinal blindness and improve vision for all.

## Encapsulation Therapy

**Figure 1:** shows a capsule containing cells that continuously secrete a drug (e.g. ciliary neurotrophic factor).



**Figure 2:** showing how the capsule is inserted into the eye.



If you would like to make a tax-deductible donation or discuss leaving a bequest to support macular research please visit our website [sydney.edu.au/save-sight-institute/support-us/donate.html](https://sydney.edu.au/save-sight-institute/support-us/donate.html) or scan the QR code.



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