

AN EMOTIONAL JOURNEY OF  
DISCOVERY FROM DARKNESS INTO THE LIGHT

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A movie by Efthimis Hatzis

# RARE LAND



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**MOVIE PREMIERE – SAVE THE DATE**

Industry Expert Theater  
Tuesday 6th February 2024 | 3.00-4.00 pm | Seaport Foyer

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# AGENDA

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- 3.00 pm**    **WELCOME AND INTRODUCTION OF THE PANEL SPEAKERS**  
Stuart Siedman
- 3.10 pm**    **RARE LAND MOVIE SCREENING**
- 3.40 pm**    **A LONG JOURNEY CALLED ALPHA-MANNOSIDOSIS - ROUND TABLE**  
Prof. Robert J. Hopkin, Prof. Martin Magner, Stuart Siedman
- 3.50 pm**    **Q&A SESSION**  
Prof. Robert J. Hopkin, Prof. Martin Magner, Stuart Siedman
- 3.55 pm**    **CLOSING REMARKS**  
Stuart Siedman
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## **GUEST SPEAKERS**

We are delighted to welcome our experts for a round table discussion on the journey to a diagnosis of alpha-mannosidosis.

### **PANEL SPEAKERS:**

#### **Ass. Prof. Martin Magner**

MD, PhD, Department of Pediatrics and Inherited Metabolic Disorders, General University Hospital, Prague

#### **Ass. Prof. Robert J. Hopkin**

Associate Professor,  
UC Department of Pediatrics  
Cincinnati Children's Hospital  
Medical Center, Ohio (USA)

### **MODERATOR:**

#### **Stuart Siedman**

Global Head Patient Advocacy  
Rare Disease, Chiesi Global Rare  
Diseases

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## RARE LAND – SYNOPSIS

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***Rare Land* is an emotional journey of discovery from darkness into the light.**

On a beautiful summer day, Alexandros cycles along a pier in a remote seaside village in Greece with his brother. As he pedals precariously close to the edge of the pier, the idyllic scene is shattered when he is overcome by a strange dizziness and tumbles into the sea.

The road ahead for Alexandros and his family is one of both fear and hope, as they enter the uncertainty and uncharted territory of coping with alpha-mannosidosis. Together they search for answers, and are guided by an American doctor who helps them strive to overcome the obstacles they face. We, the viewers, are invited to bear witness to their journey as they navigate the struggles and challenges of this rare disease. Will Alexandros find the breakthrough he so desperately needs?

**A rare disease is like a rare land ...**

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# BEHIND THE SCENES OF RARE LAND

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## **Comments from screenwriter Nancy Spetsioti and director Efthimis Hatzis**

“This film is loosely inspired by the true story of a boy with a rare disease. However, it is a universal story about people confronting and overcoming their fears.

Disease can cause harm, but harm does not cause disability. Disability is a social construct, created by the barriers society puts in the way of people who stray from the social norm of able-bodiedness.

*Rare Land* aims to address some of these barriers and illuminate acceptance; ultimately being a journey of truth, introspection, acceptance and love.”

## **Screenwriter Nancy Spetsioti**



“Our protagonist sees his individuality as a gift. He sees life from a rare, unique point of view. Blue sky, golden wheat, sea, breeze, mud, breathe.”

## **Director Efthimis Hatzis**

**Join us for an emotional journey through a RARE LAND**

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Production made possible thanks to the unconditional support of  
Chiesi Farmaceutici S.p.A.

Produced by View Master Films

PP-VA-0156 V2.0

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