

# WE NEED YOUR HELP

## The Situation

On Tuesday 21 May PHARMAC, the NZ Government's medicines funding agency, abruptly ended negotiations to provide patients living with the devastating PNH disease, with access to the life-saving treatment, Soliris. Without this treatment, PNH patients have a median survival of just 10 years.

PHARMAC have now opened a public consultation, seeking submissions in relation to their proposal to **decline** funding for Soliris. In the documents provided PHARMAC present PNH patients in desperate need of a treatment acknowledged as highly effective, as an unwanted burden to the health system.

For the with 22 patients diagnosed with PNH in New Zealand PNH and the approximately 8 considered to have severe disease the situation is dire.

PNHSANZ ask that you express your support for PNH patients in New Zealand by making a submission to PHARMAC **before 31 July**.

## What You Can Do

We need you to tell PHARMAC it is **unacceptable** to let people die when a life saving treatment is available.

We would also like you to send the same submission to PHARMAC's Decision Criteria review panel as rare disease patients **should not** be made to fight for access to new treatments.

Submissions must be sent to PHARMAC **before Wednesday 31 July**.

*Please personalise the below template and email to BOTH addresses detailed*

Email: [eculizumabfeedback@pharmac.govt.nz](mailto:eculizumabfeedback@pharmac.govt.nz)

Email: [opp@pharmac.govt.nz](mailto:opp@pharmac.govt.nz)

**Subject:** Submission to PHARMAC's Proposal to decline a funding application for Soliris (eculizumab)

To Whom it May Concern;

I support PNH patients in New Zealand in their fight to gain access to the life saving treatment Soliris.

I DO NOT support PHARMAC's proposal to decline funding for the Soliris treatment.

I support the PNH Support Association's proposition for Equity and Fairness which states:

- i. **PHARMAC must return to the negotiating table** with the supplier of the Soliris treatment
- ii. **PHARMAC must negotiate in good faith** toward funding Soliris for a minimum of 8 NZ PNH patients
- iii. **PHARMAC must establish fair assessment criteria**, based on expert advice from the international haematological community, to assess patient need for the Soliris treatment
- iv. **PHARMAC must amend its Operating Policies and Procedures** to acknowledge the right of rare disease patients to access life restoring and life saving treatments as in the specific example of the Soliris treatment

*(please include your personal statements here)*

Yours faithfully

## The real cost

The real cost of PHARMAC's proposal to decline funding for the Soliris treatment is the lost contributions of the New Zealanders affected by the PNH disease.

These are the people who, through no fault of their own, are struggling with a devastating disease and who are now being told by PHARMAC: your lives are not worth saving.



## PHARMAC: In their own words

**PTAC Meeting**, 16 & 17 February 2012

Key points:

- ⤴ No haematologists with experience of Soliris treatment appointed to specialist subcommittee
- ⤴ Survival gains of 32.5 years dismissed
- ⤴ Cost highlighted as major issue

**Haematology Subcommittee**, 6 August 2012

Key points:

- ⤴ Recommend Soliris treatment be funded
- ⤴ Suggest an advisory panel be established
- ⤴ Propose selection criteria for treatment
- ⤴ Consider efficacy data to be of medium strength
- ⤴ Describe a high clinical need
- ⤴ Conclude that there is no clinical reason not to fund the treatment

**PTAC Meeting**, 18 March 2013

Key points:

- ⤴ Note excellent evidence for Soliris stopping destructive processes of PNH disease
- ⤴ Note good evidence for restored quality of life
- ⤴ State survival benefit "likely"
- ⤴ Confirm there are no alternative treatments
- ⤴ Note that all patients could benefit from Soliris treatment
- ⤴ Agree to selection criteria for treatment
- ⤴ Recommend not to fund treatment