

Questions for survey:

Section A: Personal details

Please give us a background on your child.

Section B: Cancer Journey

Please give us a background on your child's cancer journey.

Section C: Rule 8.1b

Prior to Pharmac's consultation, were you aware of the existence of Rule 8.1b? Yes No

What has been your understanding about how cancer treatment (drugs/trials) are accessed/funded in NZ: *tick response that apply*

- I thought everything is fully funded
- Kids can have access to any treatment that is available overseas here in NZ
- Only some treatment is funded, some may not be
- I am not sure about access and funding

Do you know if your child accessed medication through Rule 8.1b? See a list of medications funded through Rule 8.1b [here](#). This can be both primary treatment or relapse (please provide details if possible)

No Yes

Was your child enrolled in a clinical trial? Yes No

If yes, was this in NZ or overseas? _____

Please provide details:

Did you have to access treatment outside of the NZ public health system (ie private)? Yes No

For yes, please provide details (comment box), which may include location, treatment details, how it was arranged, challenges and hurdles, who paid and if self funded, what the cost was:

Section C: Rule 8.1b Cont.

Did your child receive treatment overseas? Yes No

If yes, how was this funded? If yes, how did you pay (e.g. savings, family help, mortgage house, givealittle) and how much did it cost?

What was the impact of travelling overseas on

- Your child – friendships, development, school, etc
- Your family – siblings, parents
- Your financial situation
- Your emotional wellbeing
- Anything else:

If not, did you at any stage have to consider treatment overseas? (If so please explain circumstances, why was it considered, what was involved, outcome)

If 8.1b did not exist, what impact do you think it would have:

- On your child's future treatment:
 - In the event their current treatment doesn't work
 - *Clinical trials/access to innovative drugs, personalised treatments*
 - In the event they relapse

If 8.1b did not exist, what impact do you think it would have:

- On other newly diagnosed children:

- On you as a whanau/family:

Any other comments

For any other information you would like to include, please write it here: