

Welcome to the Understanding Modifiers of TRPC6 kidney disease (UMoT) study survey.

You are invited to participate in a research study that aims to better describe the range of clinical experiences in individuals who have inherited the *TRPC6* gene variant associated with focal segmental glomerulosclerosis (FSGS), and to seek genetic factors that modify the clinical course of this disease.

Participation is voluntary. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you decide to take part now but change your mind later, you can pull out of the study at any time.

Please ensure you have read and understood the Patient Information Sheet and completed the consent forms before starting the survey.

If you would like a copy of your responses, please let us know and we can arrange a PDF copy to be sent to you via email.

Thank you for your participation.

**Contact Details** 

**UMoT Study Team** 

Email: umots@otago.ac.nz

Phone: 03 244 1147



## **Participant Details**

Full name		
Date of Birth		
Sex	<ul><li>○ Male</li><li>○ Female</li><li>○ Other</li><li>○ Do not wish to comment</li></ul>	
Please specify Other if you wish to		
Ethnicity	<ul> <li>New Zealand European</li> <li>Māori</li> <li>Samoan</li> <li>Cook Islands Māori</li> <li>Tongan</li> <li>Niuean</li> <li>Chinese</li> <li>Indian</li> <li>Other (please specify below)</li> </ul>	
Please enter up to three other ethnicities		
Specify Iwi (please write unknown if you are unsure)		
Height (in cm or feet and inches i.e., 5ft7)		
Weight (in kg or pounds)		
Are you a smoker?	<ul><li>○ Current</li><li>○ Never</li><li>○ Ex-smoker</li></ul>	
If yes, how many cigarettes do you/did you smoke a day?	<ul> <li>1-5 cigarettes per day</li> <li>6-10 cigarettes per day</li> <li>11-20 cigarettes per day</li> <li>21-30 cigarettes per day</li> <li>31 or more cigarettes per day</li> </ul>	

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### **Participant Details**

Occupation	<ul> <li>Manager</li> <li>Professional</li> <li>Technician and Trade Worker</li> <li>Community and Personal Service Worker</li> <li>Clerical and Administrative Worker</li> <li>Sales Worker</li> <li>Machinery Operator and Driver</li> <li>Labourer</li> <li>Retired</li> <li>Student</li> <li>Unemployed</li> </ul>
NHI number (if known)	
Email Address	
Phone Number	
Home Address	
GP Name & Address	
Genetic Details	
Have you had a gene test for the TRPC6 change (the gene that causes kidney disease in the family)?	<ul><li>○ Yes</li><li>○ No</li><li>○ Unsure</li></ul>
How old were you when you had the test?	
Did it confirm you have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Any additional details about your TRPC6 test?	
Have you undergone genetic testing, other than the TRPC6 genetic test? If so, please provide any details.	
Aside from TRPC6, have you or anyone in your family ever been diagnosed with a genetic disorder or syndrome?	
Have you or any family members participated in genetic research or studies? If yes, please provide details.	





#### **Clinical Details**

Have you been told you have kidney function problems?	<ul><li>○ Yes</li><li>○ No</li><li>○ Unsure</li></ul>
What was your diagnosis?	
How old were you when it was first noticed?	
Have you reached end stage kidney disease (dialysis or kidney transplant)? If yes, how old were you when this happened?	
Have you ever had protein detected in your urine?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
How old were you when protein was first detected in your urine?	
Was it persistent?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Have you ever had visible blood in your urine?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Do you have high blood pressure?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
What age were you diagnosed?	
Do you experience significant ankle swelling?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Have you ever had gout?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Do you have diabetes or high blood sugar levels?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Type I or Type II diabetes?	<ul><li> Type I</li><li> Type II</li><li> Unsure</li></ul>
How old were you when your diabetes or high blood sugar levels were detected?	

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#### **Clinical Details**

Have you ever been or are you curre	ntly pregnant?	<ul><li>○ Yes</li><li>○ No</li><li>○ Unsure</li></ul>	
During pregnancy, did you experience following:	e any of the	☐ High blood pressure ☐ Protein in your urine ☐ Pre-eclampsia	(during or after pregnancy)
Do you have a history of the f	ollowing:		
	Yes	No	Unsure
Heart attack	0	0	0
Heart failure	0	0	0
Stroke	0	0	0
Circulation disease in your legs (I.e., swelling)	0	0	0
Charcot Marie Tooth Neuropathy	0	0	0





### **Family Details - Mother**

Please fill out the following information for your **biological mother** to the best of your knowledge.

Full Name		
Date of Birth (D/M/Y) Birth year is acceptable if you are unsure.		
Have they had any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Choose any that you think they have	<ul> <li>☐ Kidney function problems</li> <li>☐ High blood pressure</li> <li>☐ Protein in the urine</li> <li>☐ Dialysis</li> <li>☐ Kidney transplant</li> <li>☐ Other (please specify)</li> </ul>	
Please specify Other		
Please indicate if your biological mother is related to the TRPC6 family.	○ Yes ○ No	
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
When was the test confirmed?		
Are they alive?	○ Yes ○ No	
What was their age at death?		
Cause of death?		
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### **Family Details - Father**

Please fill out the following information for your **biological father** to the best of your knowledge.

Full Name	
Date of Birth (D/M/Y) Birth year is acceptable if you are unsure.	
Have they had any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Choose any that you think they have	<ul> <li>☐ Kidney function problems</li> <li>☐ High blood pressure</li> <li>☐ Protein in the urine</li> <li>☐ Dialysis</li> <li>☐ Kidney transplant</li> <li>☐ Other (please specify)</li> </ul>
Please specify Other	
Please indicate if your biological father is related to the TRPC6 family.	○ Yes ○ No
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
When was the test confirmed?	
Are they alive?	○ Yes ○ No
What was their age at death?	
Cause of death?	
Change?  Did it confirm that they have the gene change that may cause kidney disease?  When was the test confirmed?  Are they alive?  What was their age at death?	No Unsure  Yes No Unsure  Yes Yes

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### **Family Details - Grandmother**

Please fill out the following information for your **grandmother** from the TRPC6 family to the best of your knowledge.

Full Name		
Date of Birth (D/M/Y) Birth year is acceptable if you are unsure.		
Have they had any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Choose any that you think they have	<ul> <li>☐ Kidney function problems</li> <li>☐ High blood pressure</li> <li>☐ Protein in the urine</li> <li>☐ Dialysis</li> <li>☐ Kidney transplant</li> <li>☐ Other (please specify)</li> </ul>	
Please specify Other		
Please indicate if your grandmother is related to the TRPC6 family.	○ Yes ○ No	
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
When was the test confirmed?		
Are they alive?	○ Yes ○ No	
What was their age at death?		
Cause of death?		
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### **Family Details - Grandfather**

Please fill out the following information for your **grandfather** from the TRPC6 family to the best of your knowledge.

ruii name		
Date of Birth (D/M/Y) Birth year is acceptable if you are unsure.		
Have they had any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Choose any that you think they have	<ul> <li>☐ Kidney function problems</li> <li>☐ High blood pressure</li> <li>☐ Protein in the urine</li> <li>☐ Dialysis</li> <li>☐ Kidney transplant</li> <li>☐ Other (please specify)</li> </ul>	
Please specify Other		
Please indicate if your grandfather is related to the TRPC6 family.	○ Yes ○ No	
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
When was the test confirmed?		
Are they alive?	○ Yes ○ No	
What was their age at death?		
Cause of death?		
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### **Family Details - Siblings**

Please fill out the following information for your **siblings** to the best of your knowledge. If you do not have siblings, please continue to the next section.

Full Name		
Date of Birth (D/M/Y) Birth year is acceptable if you are unsure.		
Sex	<ul><li>○ Male</li><li>○ Female</li><li>○ Other</li></ul>	
Please specify Other if you wish to		
Please indicate whether your sibling is one of the following:	<ul><li>Full sibling</li><li>Half sibling (TRPC6 family)</li><li>Half-sibling (non-TRPC6 family)</li><li>Step sibling</li></ul>	
Do they have any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Choose any that you think they have:	<ul> <li>☐ Kidney function problems</li> <li>☐ High blood pressure</li> <li>☐ Protein in the urine</li> <li>☐ Dialysis</li> <li>☐ Kidney transplant</li> <li>☐ Other (please specify)</li> </ul>	
Please specify Other		
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
When was the test confirmed?		
Are they alive?	○ Yes ○ No	
What was their age at death?		
Cause of death?		



## **Family Details - Siblings**

Full Name	
Date of Birth (D/M/Y) Birth year is acceptable if you are unsure.	
Sex	<ul><li> Male</li><li> Female</li><li> Other</li></ul>
Please specify Other if you wish to	
Please indicate whether your sibling is one of the following:	<ul><li>Full sibling</li><li>Half sibling (TRPC6 family)</li><li>Half-sibling (non-TRPC6 family)</li><li>Step sibling</li></ul>
Do they have any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Choose any that you think they have:	☐ Kidney function problems ☐ High blood pressure ☐ Protein in the urine ☐ Dialysis ☐ Kidney transplant ☐ Other (please specify)
Please specify Other	
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
When was the test confirmed?	
Are they alive?	○ Yes ○ No
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Cause of death?	

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## **Family Details - Siblings**

Full Name	
Date of Birth (D/M/Y) Birth year is acceptable if you are unsure.	
Sex	<ul><li> Male</li><li> Female</li><li> Other</li></ul>
Please specify Other if you wish to	
Please indicate whether your sibling is one of the following:	<ul><li>Full sibling</li><li>Half sibling (TRPC6 family)</li><li>Half-sibling (non-TRPC6 family)</li><li>Step sibling</li></ul>
Do they have any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Choose any that you think they have:	☐ Kidney function problems ☐ High blood pressure ☐ Protein in the urine ☐ Dialysis ☐ Kidney transplant ☐ Other (please specify)
Please specify Other	
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
When was the test confirmed?	
Are they alive?	○ Yes ○ No
What was their age at death?	
Cause of death?	

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### **Family Details - Siblings**

If you have more siblings, there are extra pages at the end of this document where you can provide their information.

Full Name		
Date of Birth (D/M/Y) Birth year is acceptable if you are unsure.		
Sex	<ul><li>○ Male</li><li>○ Female</li><li>○ Other</li></ul>	
Please specify Other if you wish to		
Please indicate whether your sibling is one of the following:	<ul><li>○ Full sibling</li><li>○ Half sibling (TRPC6 family)</li><li>○ Half-sibling (non-TRPC6 family)</li><li>○ Step sibling</li></ul>	
Do they have any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Choose any that you think they have:	<ul> <li>☐ Kidney function problems</li> <li>☐ High blood pressure</li> <li>☐ Protein in the urine</li> <li>☐ Dialysis</li> <li>☐ Kidney transplant</li> <li>☐ Other (please specify)</li> </ul>	
Please specify Other		
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
When was the test confirmed?		
Are they alive?	○ Yes ○ No	
What was their age at death?		
Cause of death?		



### **Family Details - Children**

Please fill out the following information for your **children**. If you do not have children, please continue to the next section.

Full name	
Date of Birth (D/M/Y)	
Sex	<ul><li> Male</li><li> Female</li><li> Other</li></ul>
Please specify Other if you wish to	
Second parent full name	
Please indicate if your child is your step-child.	○ Yes ○ No
Do they have any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Choose any that you think they have:	☐ Kidney function problems ☐ High blood pressure ☐ Protein in the urine ☐ Dialysis ☐ Kidney transplant ☐ Other (please specify)
Please specify Other	
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
When was the test confirmed?	
Are they alive?	○ Yes ○ No
What was their age at death?	
Cause of death?	



## **Family Details - Children**

Full name		
Date of Birth (D/M/Y)		
Sex	<ul><li>○ Male</li><li>○ Female</li><li>○ Other</li></ul>	
Please specify Other if you wish to		
Second parent full name		
Please indicate if your child is your step-child.	○ Yes ○ No	
Do they have any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Choose any that you think they have:	<ul> <li>☐ Kidney function problems</li> <li>☐ High blood pressure</li> <li>☐ Protein in the urine</li> <li>☐ Dialysis</li> <li>☐ Kidney transplant</li> <li>☐ Other (please specify)</li> </ul>	
Please specify Other		
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
When was the test confirmed?		
Are they alive?	○ Yes ○ No	
What was their age at death?		
Cause of death?		

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## **Family Details - Children**

Full name		
Date of Birth (D/M/Y)		
Sex	<ul><li>○ Male</li><li>○ Female</li><li>○ Other</li></ul>	
Please specify Other if you wish to		
Second parent full name		
Please indicate if your child is your step-child.	○ Yes ○ No	
Do they have any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Choose any that you think they have:	<ul> <li>☐ Kidney function problems</li> <li>☐ High blood pressure</li> <li>☐ Protein in the urine</li> <li>☐ Dialysis</li> <li>☐ Kidney transplant</li> <li>☐ Other (please specify)</li> </ul>	
Please specify Other		
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
When was the test confirmed?		
Are they alive?	○ Yes ○ No	
What was their age at death?		
Cause of death?		

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#### **Family Details - Children**

If you have more children, there are extra pages at the end of this document where you can provide their information.

○ Male	
○ Female ○ Other	
○ Yes ○ No	
<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
☐ Kidney function problems ☐ High blood pressure ☐ Protein in the urine ☐ Dialysis ☐ Kidney transplant ☐ Other (please specify)	
<ul><li>○ Yes</li><li>○ No</li><li>○ Unsure</li></ul>	
<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
○ Yes ○ No	
	Female   Other



## **Family Details - Extended Family**

Has anyone else within your extended family suffered from kidney problems? If so, please state any clinical diagnoses and their relation to you.		
Is there anything else you would like to add about yourself or your family?		
Would you like a PDF of your reponses emailed to you?  O Yes  No		

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### The following questions are not mandatory.

What is your understanding of TRPC6 and how it affects your family?		
What would you like to get out of this study? What would be a good outcome of this study for you?		
Do you know of anyone else in your family who would like to be involved in this study? If so, please provide their name and a method to get in contact (preferably an email address, or a phone number).		

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Thank you for taking the time to complete this survey! Your participation in this study is greatly appreciated.

If you would like a copy of your responses, please let us know and we can arrange a PDF copy to be sent to you via email.

If you have any questions or feedback, please feel free to contact us.

#### **Contact Details**

**UMoT Study Team** 

Email: umots@otago.ac.nz

Phone: 03 244 1147



### **Family Details - Siblings**

Please fill out the following information for your **siblings** to the best of your knowledge.

Full Name		
Date of Birth (D/M/Y) Birth year is acceptable if you are unsure.		
Sex	<ul><li></li></ul>	
Please specify Other if you wish to		
Please indicate whether your sibling is one of the following:	<ul> <li>Full sibling</li> <li>Half sibling (TRPC6 family)</li> <li>Half-sibling (non-TRPC6 family)</li> <li>Step sibling</li> </ul>	
Do they have any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Choose any that you think they have:	<ul> <li>☐ Kidney function problems</li> <li>☐ High blood pressure</li> <li>☐ Protein in the urine</li> <li>☐ Dialysis</li> <li>☐ Kidney transplant</li> <li>☐ Other (please specify)</li> </ul>	
Please specify Other		
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
When was the test confirmed?		
Are they alive?	○ Yes ○ No	
What was their age at death?		
Cause of death?		



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Please fill out the following information for your **siblings** to the best of your knowledge.

Full Name		
Date of Birth (D/M/Y) Birth year is acceptable if you are unsure.		
Sex	<ul><li></li></ul>	
Please specify Other if you wish to		
Please indicate whether your sibling is one of the following:	<ul> <li>Full sibling</li> <li>Half sibling (TRPC6 family)</li> <li>Half-sibling (non-TRPC6 family)</li> <li>Step sibling</li> </ul>	
Do they have any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Choose any that you think they have:	<ul> <li>☐ Kidney function problems</li> <li>☐ High blood pressure</li> <li>☐ Protein in the urine</li> <li>☐ Dialysis</li> <li>☐ Kidney transplant</li> <li>☐ Other (please specify)</li> </ul>	
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Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
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When was the test confirmed?		
Are they alive?	○ Yes ○ No	
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Cause of death?		



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Please fill out the following information for your **siblings** to the best of your knowledge.

Full Name		
Date of Birth (D/M/Y) Birth year is acceptable if you are unsure.		
Sex	<ul><li></li></ul>	
Please specify Other if you wish to		
Please indicate whether your sibling is one of the following:	<ul> <li>Full sibling</li> <li>Half sibling (TRPC6 family)</li> <li>Half-sibling (non-TRPC6 family)</li> <li>Step sibling</li> </ul>	
Do they have any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Choose any that you think they have:	<ul> <li>☐ Kidney function problems</li> <li>☐ High blood pressure</li> <li>☐ Protein in the urine</li> <li>☐ Dialysis</li> <li>☐ Kidney transplant</li> <li>☐ Other (please specify)</li> </ul>	
Please specify Other		
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
When was the test confirmed?		
Are they alive?	○ Yes ○ No	
What was their age at death?		
Cause of death?		



### **Family Details - Siblings**

Please fill out the following information for your **siblings** to the best of your knowledge.

Full Name		
Date of Birth (D/M/Y) Birth year is acceptable if you are unsure.		
Sex	<ul><li></li></ul>	
Please specify Other if you wish to		
Please indicate whether your sibling is one of the following:	<ul> <li>Full sibling</li> <li>Half sibling (TRPC6 family)</li> <li>Half-sibling (non-TRPC6 family)</li> <li>Step sibling</li> </ul>	
Do they have any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Choose any that you think they have:	<ul> <li>☐ Kidney function problems</li> <li>☐ High blood pressure</li> <li>☐ Protein in the urine</li> <li>☐ Dialysis</li> <li>☐ Kidney transplant</li> <li>☐ Other (please specify)</li> </ul>	
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Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>	
When was the test confirmed?		
Are they alive?	○ Yes ○ No	
What was their age at death?		
Cause of death?		



### **Family Details - Children**

Please fill out the following information for your children.

Full name	
Date of Birth (D/M/Y)	
Sex	<ul><li>○ Male</li><li>○ Female</li><li>○ Other</li></ul>
Please specify Other if you wish to	
Second parent full name	
Please indicate if your child is your step-child.	○ Yes ○ No
Do they have any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Choose any that you think they have:	☐ Kidney function problems ☐ High blood pressure ☐ Protein in the urine ☐ Dialysis ☐ Kidney transplant ☐ Other (please specify)
Please specify Other	
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
When was the test confirmed?	
Are they alive?	○ Yes ○ No
What was their age at death?	
Cause of death?	



### **Family Details - Children**

Please fill out the following information for your children.

Full name	
Date of Birth (D/M/Y)	
Sex	<ul><li>○ Male</li><li>○ Female</li><li>○ Other</li></ul>
Please specify Other if you wish to	
Second parent full name	
Please indicate if your child is your step-child.	○ Yes ○ No
Do they have any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Choose any that you think they have:	☐ Kidney function problems ☐ High blood pressure ☐ Protein in the urine ☐ Dialysis ☐ Kidney transplant ☐ Other (please specify)
Please specify Other	
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
When was the test confirmed?	
Are they alive?	○ Yes ○ No
What was their age at death?	
Cause of death?	



### **Family Details - Children**

Please fill out the following information for your children.

Full name	
Date of Birth (D/M/Y)	
Sex	<ul><li>Male</li><li>Female</li><li>Other</li></ul>
Please specify Other if you wish to	
Second parent full name	
Please indicate if your child is your step-child.	○ Yes ○ No
Do they have any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Choose any that you think they have:	☐ Kidney function problems ☐ High blood pressure ☐ Protein in the urine ☐ Dialysis ☐ Kidney transplant ☐ Other (please specify)
Please specify Other	
Have they had a genetic test for the TRPC6 gene change?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Did it confirm that they have the gene change that may cause kidney disease?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
When was the test confirmed?	
Are they alive?	○ Yes ○ No
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Cause of death?	



### **Family Details - Children**

Please fill out the following information for your children.

Full name	
Date of Birth (D/M/Y)	
Sex	<ul><li>Male</li><li>Female</li><li>Other</li></ul>
Please specify Other if you wish to	
Second parent full name	
Please indicate if your child is your step-child.	○ Yes ○ No
Do they have any kidney problems?	<ul><li>Yes</li><li>No</li><li>Unsure</li></ul>
Choose any that you think they have:	☐ Kidney function problems ☐ High blood pressure ☐ Protein in the urine ☐ Dialysis ☐ Kidney transplant ☐ Other (please specify)
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