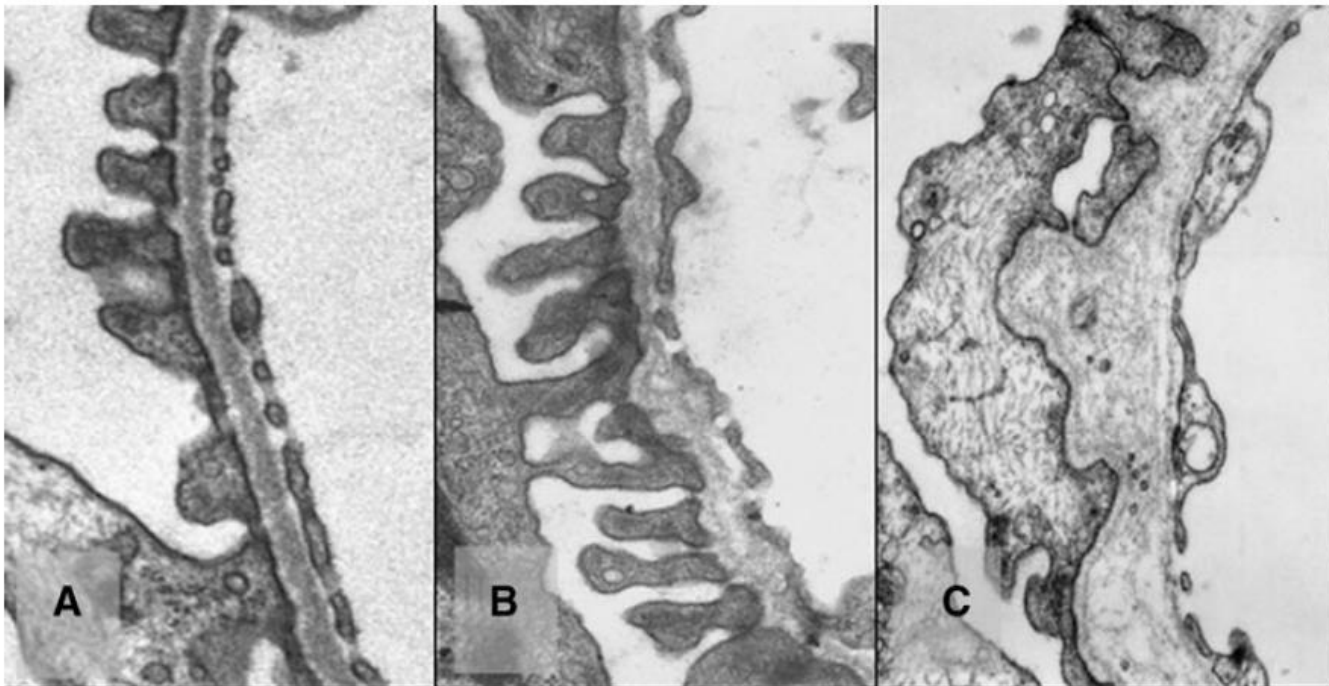


# Research and Registries

Neil Turner

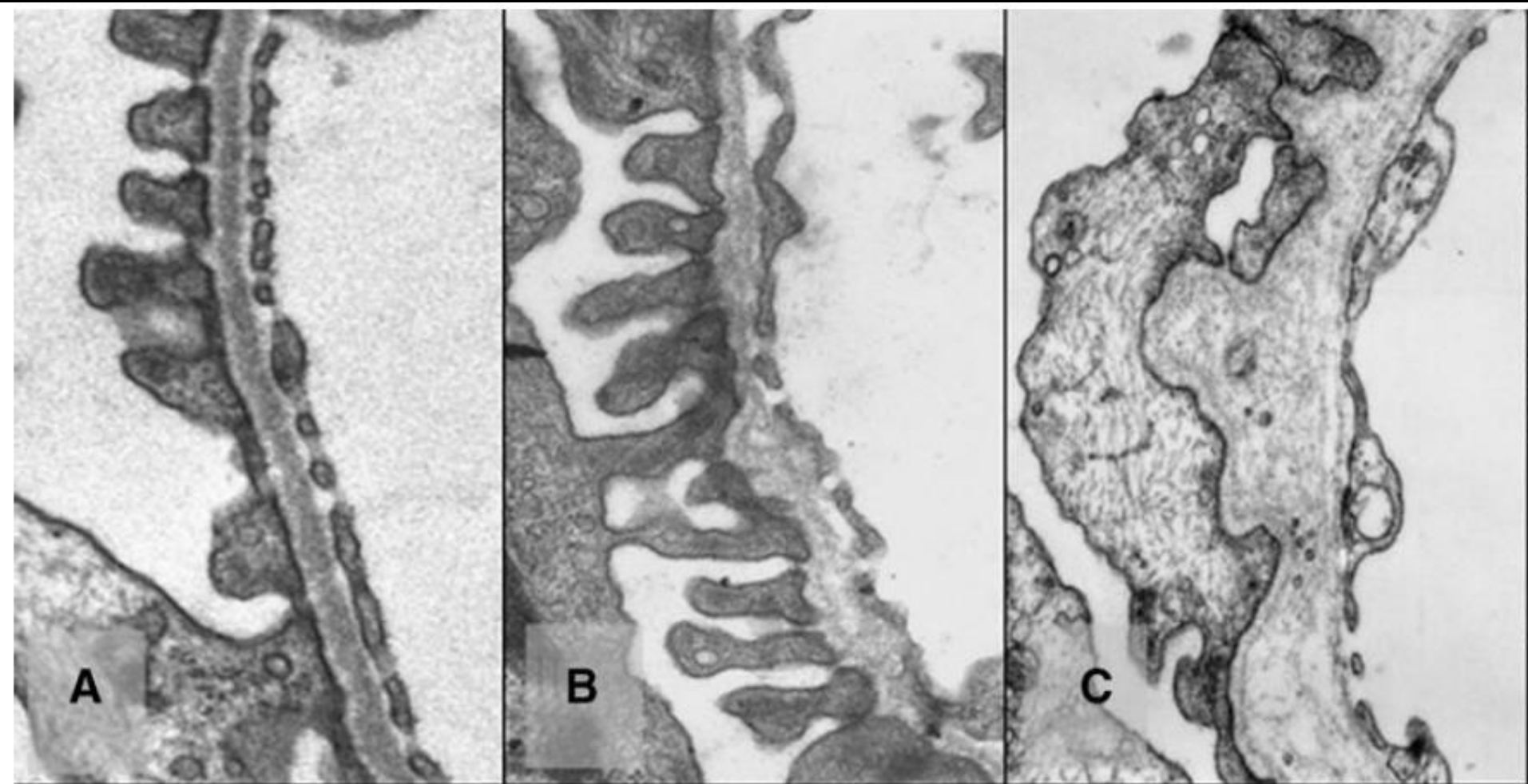


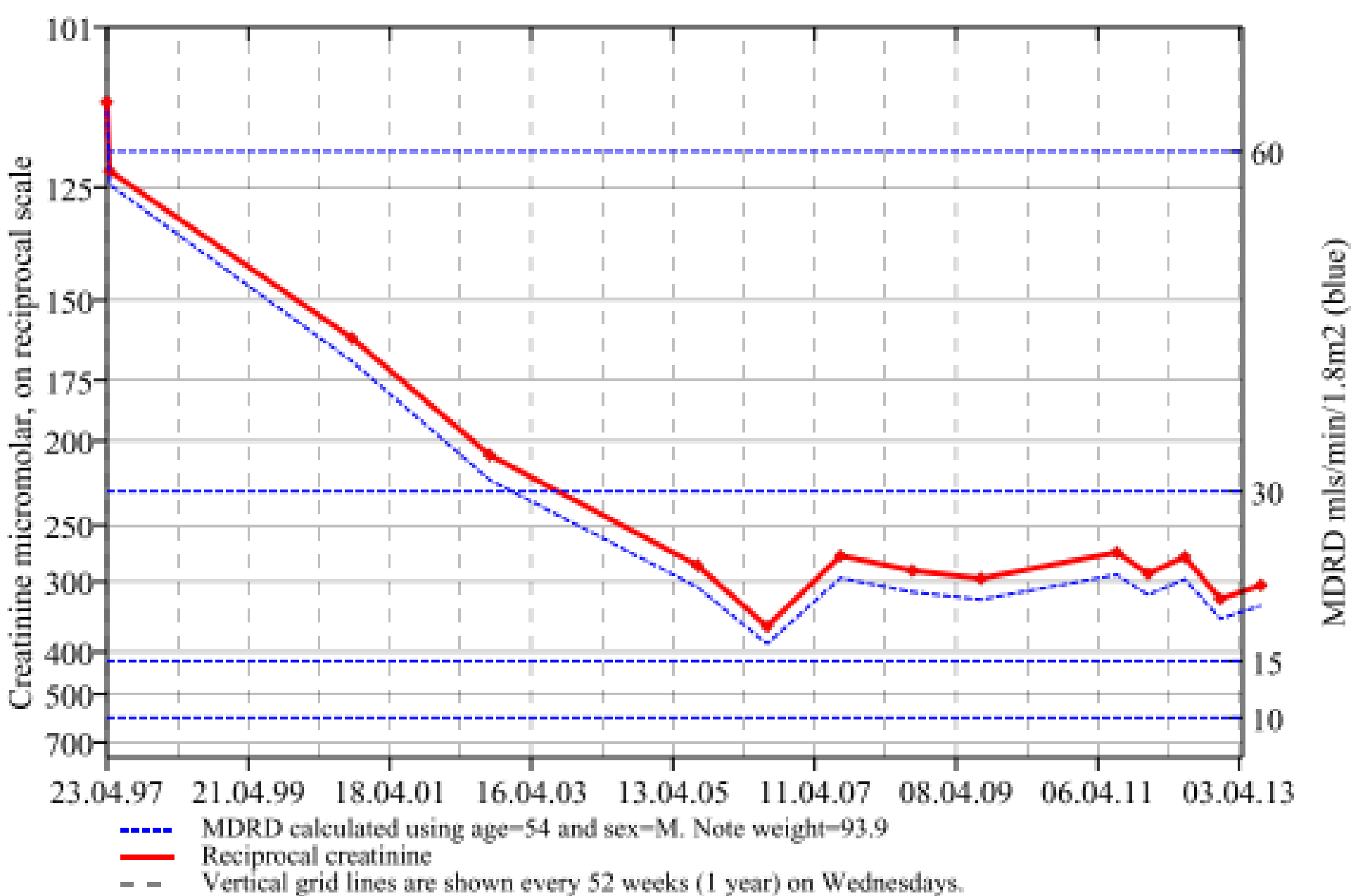


5<sup>th</sup> International Alport Workshop, Oxford Jan 2014

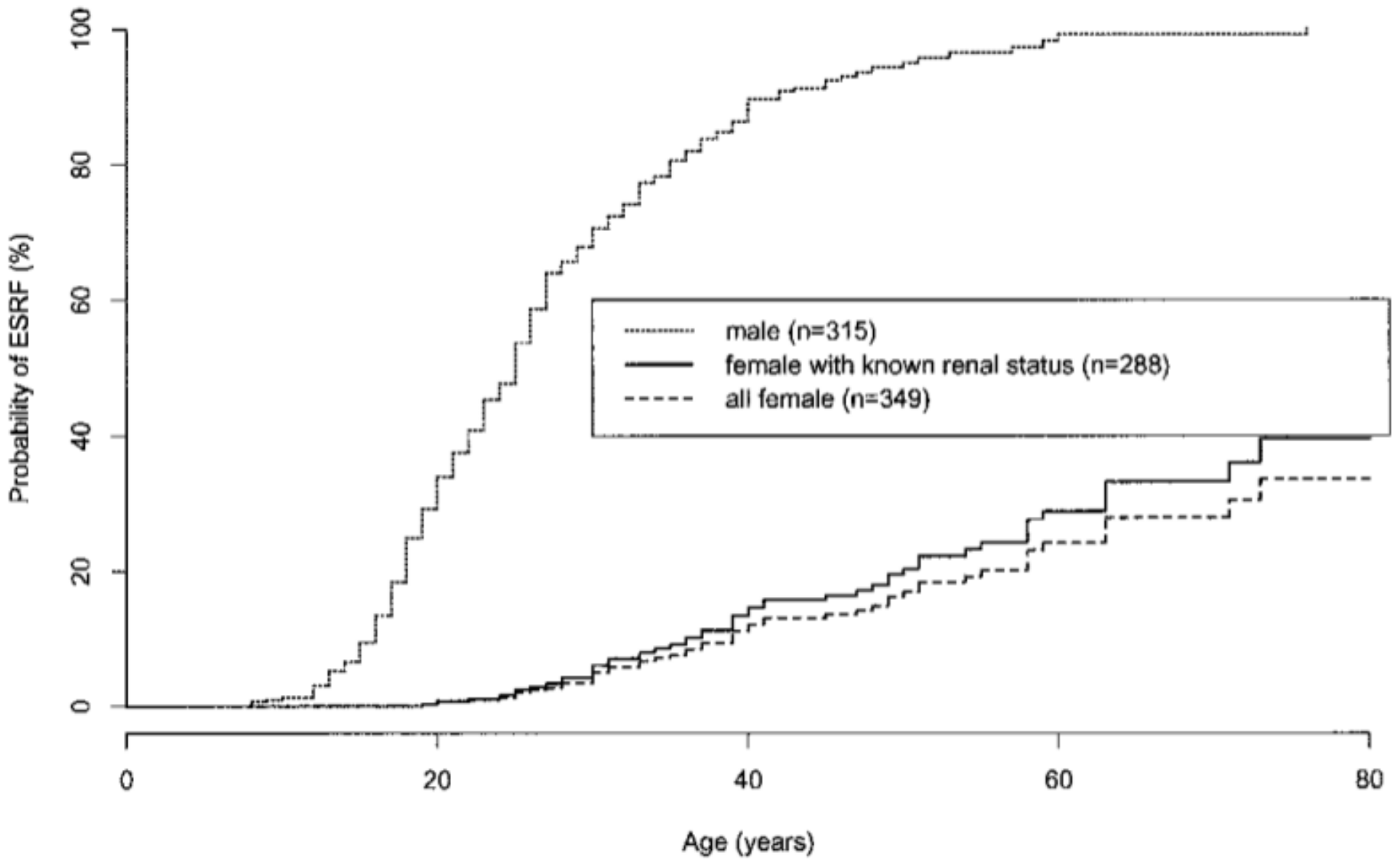
# Some important research Qs

- Can we prevent kidney failure?
- Can we prevent deafness?
- What makes some carriers get severe disease?



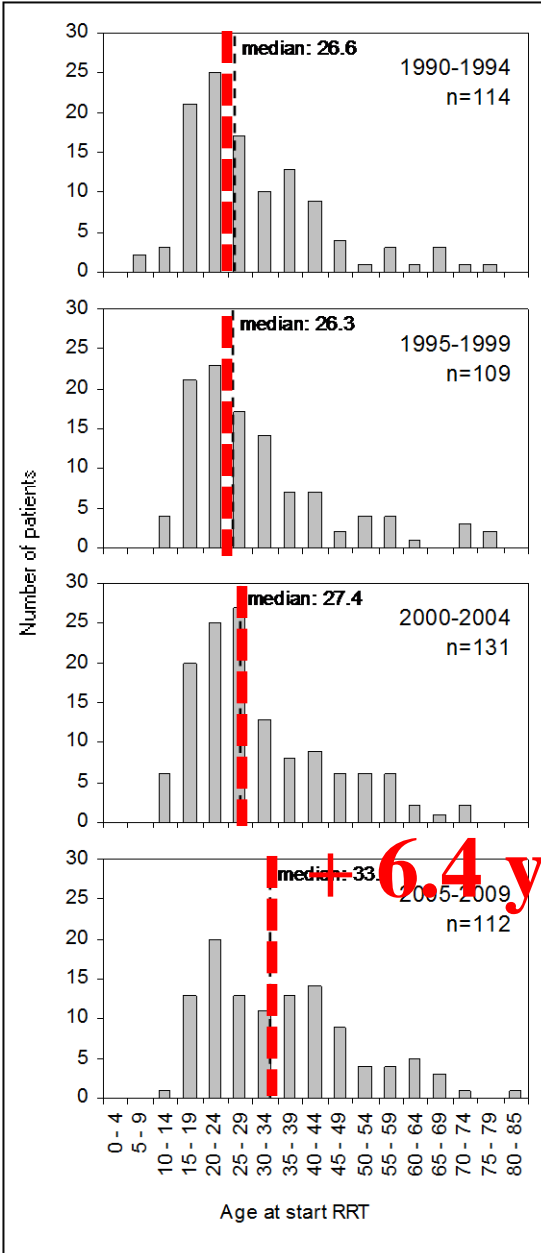


RenPlot by Richard Phelps, University of Edinburgh.

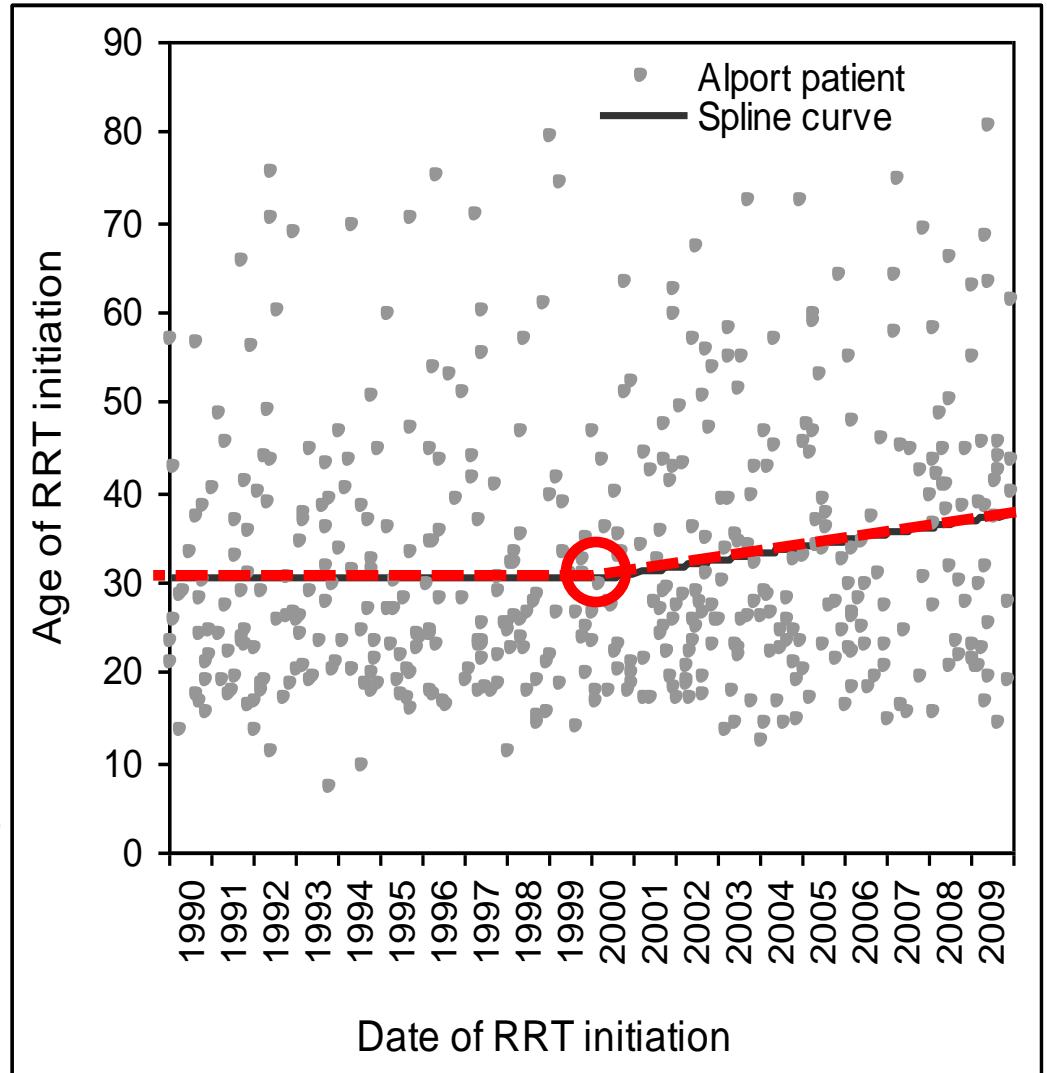


# ACE inhibitors

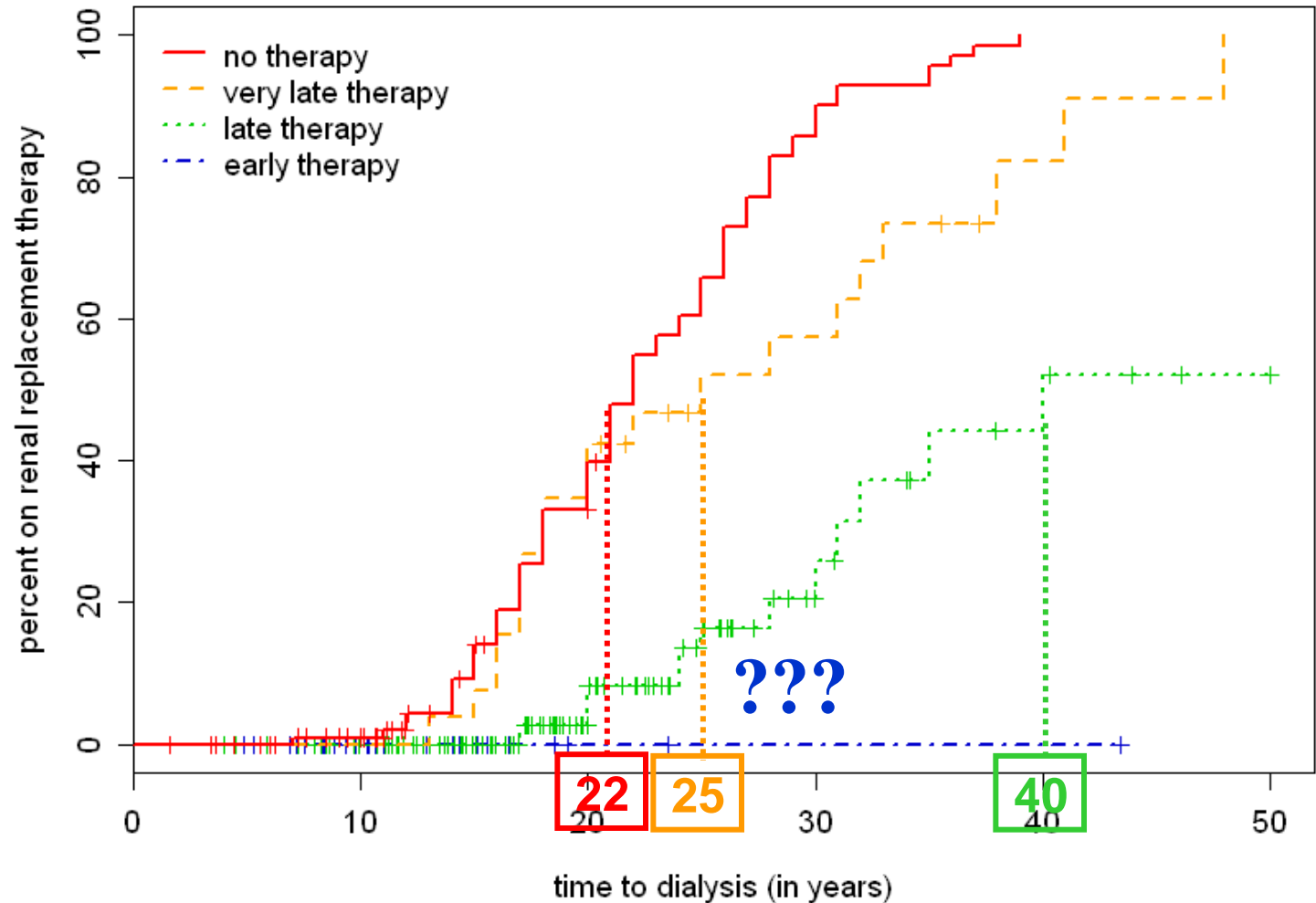
- Work in animals (mice, dogs)



**+ 6.4 years**



# Earlier treatment is better?



no. at risk

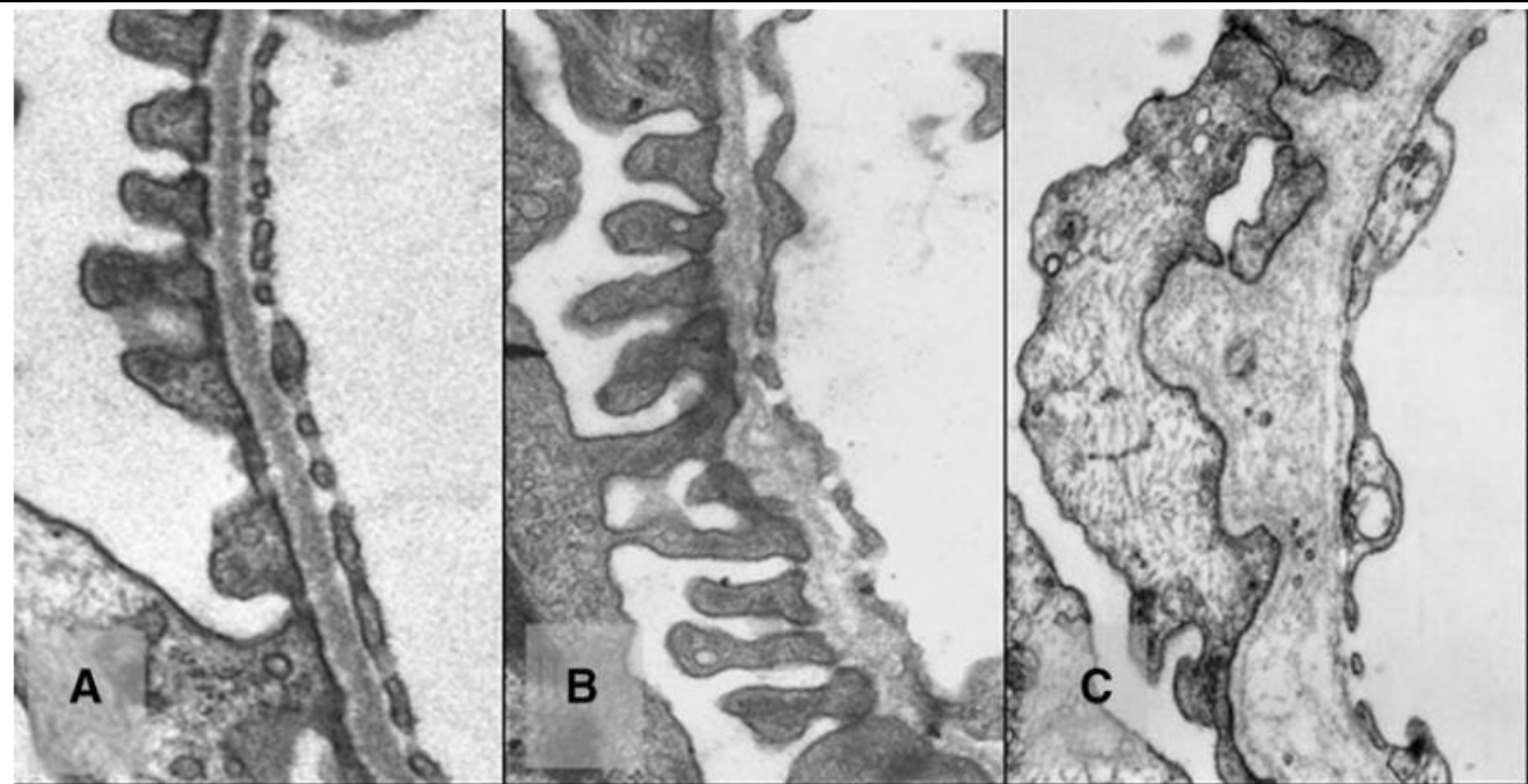
no therapy	109	105	96	75	50	29	10	5	0	0	0
very late therapy	26	26	26	25	17	10	8	5	2	1	0
late therapy	115	113	105	84	52	31	15	9	7	4	3
early therapy	33	32	20	8	2	1	1	1	1	0	0

# ACE inhibitors

- Work in animals (mice, dogs)
- Work in humans

# ACE inhibitors

- Work in animals (mice, dogs)
- Work in humans
- There are other candidate drugs



# ACE inhibitors

- Work in animals (mice, dogs)
- Work in humans
- There are other candidate drugs
  - Lower proteinuria?
  - Reduce scarring?
  - Stabilise GBM?

# ACE inhibitors now

**Anyone with proteinuria**

- 'Carrier' or fully affected

# Athena Study 2015

- 120 people in 6 countries
- Over 16; 'definite' Alport's
- **Reduced GFR – 30-75**
- Follow for two years
  - Tests every 3 months

# Athena Study 2015

- Travel and accommodation paid
- Some 'visits' at home by nurses



# Athena Study 2015

- Edinburgh and London (Royal Free)
  - Travel and accommodation paid
  - Some 'visits' at home by nurses

**To find the next drug ...**

**Get registered?**

# The UK Alport Registry

Part of **Radar**. Find everyone to:

- Learn more
- Keep them and their docs up to date
- Spot those who may be suitable for
  - New treatments
  - New studies



## Manage

your conditions and medications



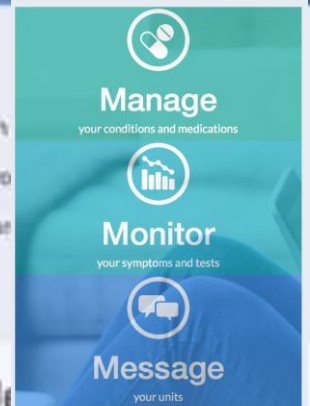
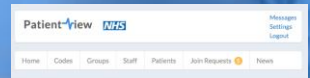
## Monitor

your symptoms and tests



## Message

your units



About Patient View  
PatientView shows your latest test results, plus info about diagnosis and treatment. You can view it from anywhere you want, and share your information...

## About Patient View

PatientView shows your latest test results, plus info about diagnosis and treatment. You can view it from anywhere you want, and share your information. Your local unit or health organisation must have joined. PatientView started out as a service for kidney patients in the UK, but can now work for others too. Information comes directly from existing records, for example hospital and GP records, or may be entered directly or via other apps. Secure messaging for...

[Tell Me More](#)

For patients

For Organisations

Latest News

Joining PatientView

What do I need to know?

No Current News

**andrew TURNER**  
 Joined 06-Sep-2011 22:45

**Last Login**  
 25-Jan-2015 22:09 from 87.114.18.157

Unread  
 Messages  
**1**

**You are a member of:**  
 Renal (Specialty) (Patient)  
 ECS (Unit) (Patient)  
 Edinburgh Royal Infirmary (Unit) (Patient)

**Data last received:**  
 23-Jan-2015 16:54 from Edinburgh Royal  
 Infirmary

## Your Settings

**Username:** turneran  
 Email: neilturn@gmail.com

[Change Your Settings/Password](#)

## Alerts

When a new result or letter arrives you might wish to be notified.  
 Click 'Show Alert Settings' to select the ones you are interested in.

### Result Alerts

Type	Latest Value	Date	New Result? (click to hide notification)
<a href="#">Creatinine</a>	72	02-Oct-2014	

### Letter Alerts

Latest Letter	Letter Type	New Letter? (click to hide notification)
Not Available	Not Available	

[Show Alert Settings](#)

## Latest News

### What's New? HOW TO USE PATIENTVIEW 2

19-Jan-2015 11:55

Existing PatientView users should find it pretty easy to use, but there are some very

[Read Story](#)

### Latest results much better (Sunday morning)

19-Jan-2015 11:45

Most records are now up to date, but we are aware of one or two exceptions, we'll check

[Read Story](#)

# My Details

Information provided by:  Edin

## Edinburgh Royal Infirmary

### Patient Details

Surname	TURNER
Forename(s)	andrew
Date of Birth	28-Apr-1956
NHS/CHI/H&SC Number	2804562611
Hospital Number	
Address	7 B Kilgraston Rd Edinburgh EH9 2DR
Phone Number(s)	0131 447 0060

### GP Details

Name	Dr M Cash
Address	Bruntsfield Medical Pract EH10 4EY

Diagnosis	<p><b>Goodpasture's disease</b></p> <p><a href="#">Goodpasture's disease (long version) from EdREN</a></p> <p><a href="#">Goodpasture's disease (short version) from EdREN</a></p>
Diagnosis Date	
Other Conditions	<p>Goodpasture's disease 1990</p> <p>Moderate renal impairment no pulmonary haemorrhage</p> <p>Treated for three months</p> <p>Rheumatoid arthritis seropositive 1996</p> <p>Sulphasalazine stopped 2000 (loss of effect)</p> <p>No erosions, full remission</p> <p>Test patient details revised 14/9/9 1407</p>
Treatment	
Transplant Status	Kidney: No status uploaded ( <a href="#">Explain This</a> )

## Unit Information

- [Patient info links from Edinburgh](#)

## Other Helpful Information

- [Kidney words explained \(EdREN\)](#)
- [Kidney and urologic diseases from the NIDDK](#)
- [Links about diseases in children \(Infokid\)](#)
- [See all our info links \(on all diseases and treatments\)](#)
- [Kidney info from the NKF](#)

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## Results

Diagnostics

Enter Your Own Results



Showing Panel: 1

Urea Creatinine Potassium BMI Ca Phos Hb WBC Plats  
eGFR Comment

Select Speciality:

Renal

Table View

1

2

3

4

5

6

Urea

About

3.7 mmol/l

Edinburgh Royal Infirmary

Source:

Showing Result: 02-Oct-2014

View More Details



Creatinine

About

72 micromol/l

Edinburgh Royal Infirmary

Source:

Showing Result: 02-Oct-2014

View More Details



Potassium

About

4.0 mmol/l

Edinburgh Royal Infirmary

Source:

Showing Result: 02-Oct-2014

View More Details



BMI

About

Not Available

View More Details



Ca

About

2.41 mmol/l

Phos

About

1.22 mmol/l

Hb

About

139 g/l

WBC

About

6.4

← Back to Results

## Creatinine

Select Result:

Creatinine

Showing Result: 02-Oct-2014

About

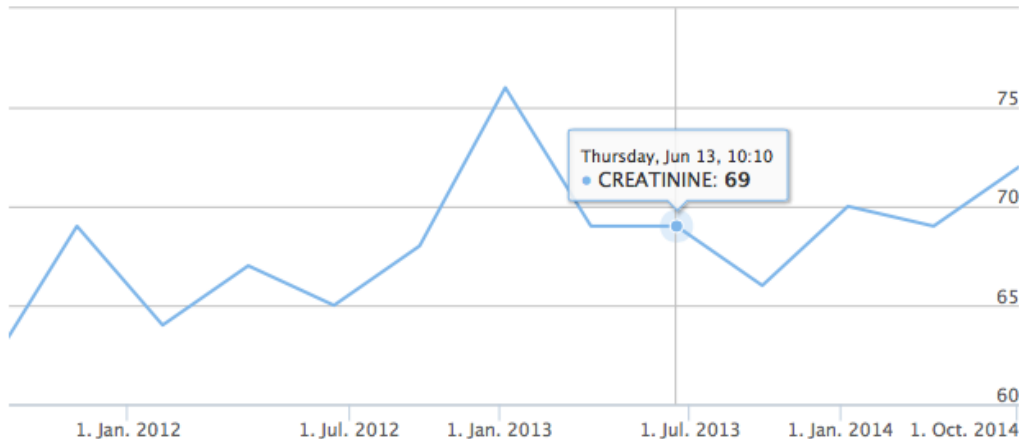
**72** micromol/l ↑ 3

Source: Edinburgh Royal Infirmary

### Comments

There are no associated comments to show

Zoom 1m 3m 1y **3y** All From Oct 3, 2011 To Oct 2, 2014



Click to select result

	Date Taken	Value	Source
	02-Oct-2014 11:00	72	Edin
	25-Jun-2014 10:50	69	Edin
	09-Jan-2014 17:30	70	Edin
	01-Oct-2013 12:30	66	Edin
	13-Jun-2013 10:10	69	Edin
	11-Apr-2013 13:00	69	Edin
	10-Jan-2013 13:30	76	Edin
	22-Aug-2012 14:15	68	Edin
	19-Jun-2012 11:25	65	Edin
	22-Apr-2012 16:15	67	Edin
	01-Feb-2012 16:35	64	Edin
	14-Nov-2011 11:30	69	Edin
	22-Sep-2011 12:15	62	Edin
	06-Jul-2011 14:15	65	Edin

← Back to Results

## Creatinine

Select Result:

Creatinine

Showing Result: 02-Oct-2014

About

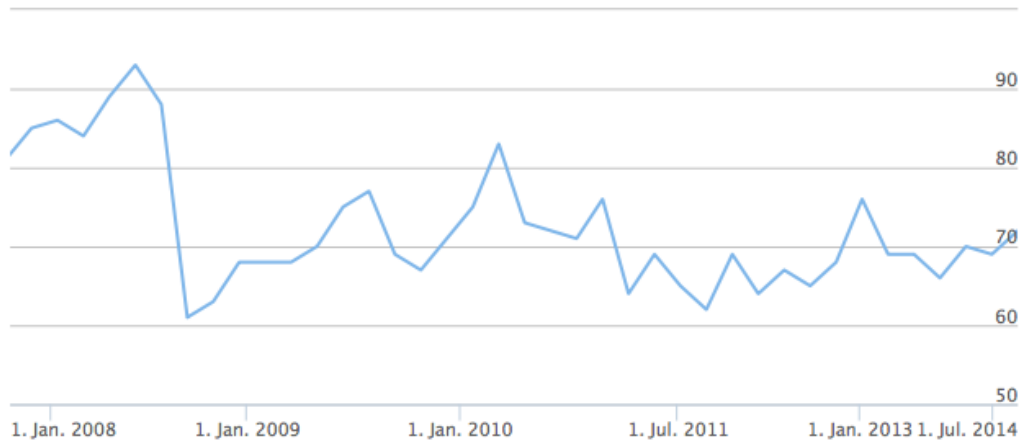
**72** micromol/l ↑ 3

Source: Edinburgh Royal Infirmary

### Comments

There are no associated comments to show

Zoom 1m 3m 1y 3y All From Nov 5, 2007 To Oct 2, 2014



Click to select result

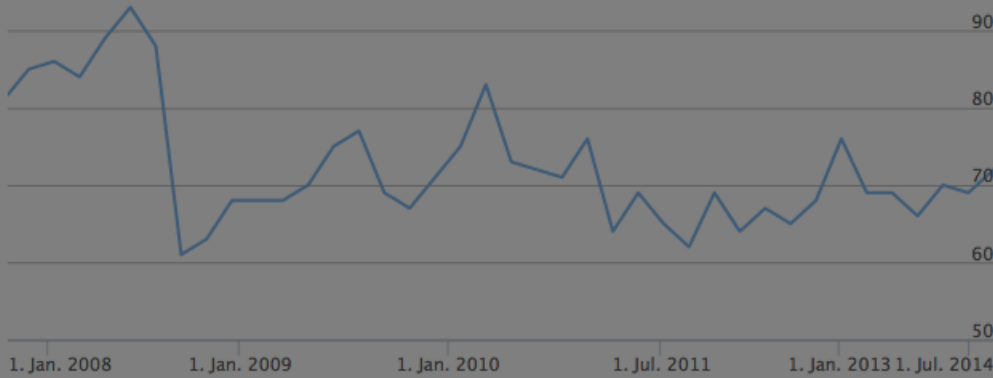
	Date Taken	Value	Source
	02-Oct-2014 11:00	72	Edin
	25-Jun-2014 10:50	69	Edin
	09-Jan-2014 17:30	70	Edin
	01-Oct-2013 12:30	66	Edin
	13-Jun-2013 10:10	69	Edin
	11-Apr-2013 13:00	69	Edin
	10-Jan-2013 13:30	76	Edin
	22-Aug-2012 14:15	68	Edin
	19-Jun-2012 11:25	65	Edin
	22-Apr-2012 16:15	67	Edin
	01-Feb-2012 16:35	64	Edin
	14-Nov-2011 11:30	69	Edin
	22-Sep-2011 12:15	62	Edin
	06-Jul-2011 14:15	65	Edin

# Creatinine Information

Name	Creatinine
Heading	Creatinine
Code	creatinine
Units	micromol/l
Normal Range	60-120
Decimal Places	Not Available
Information	<a href="http://www.rixg.org/results/creatinine.html">http://www.rixg.org/results/creatinine.html</a>

Close

Zoom 1m



	11-Apr-2013 13:00	69	Edin
	10-Jan-2013 13:30	76	Edin
	22-Aug-2012 14:15	68	Edin
	19-Jun-2012 11:25	65	Edin
	22-Apr-2012 16:15	67	Edin
	01-Feb-2012 16:35	64	Edin
	14-Nov-2011 11:30	69	Edin
	22-Sep-2011 12:15	62	Edin
	06-Jul-2011 14:15	65	Edin

## Creatinine [Creat]

This is the best routine blood test for measuring how well kidneys are working. It is produced by muscles and put out by the kidneys. Because it is produced by the muscles, it tends to be higher in muscular people, so that a weightlifter with normal kidney function will have more creatinine in their blood than a little old lady. Normal = 60-120 micromol/litre (0.7-1.4 mg/dl).

Name

Heading

Code

Units

Normal Range

Decimal Places

Information

Result	Comments
<b>less than 60</b>	Suggests a very small person, or someone with little muscle (including small children).
<b>60-120</b>	'Normal' - but there could still be reduced kidney function (see below)
<b>120-200</b>	Mild to moderate kidney failure - but in someone with little muscle, 200 could sometimes mean more severe kidney failure.
<b>300+</b>	Moderate to severe kidney failure. Most dialysis patients have creatinine measurements over 300 all of the time.

Creatinine measurement methods vary, so the same blood samples may give slightly different results in two different labs. They also vary from day to day, so small % changes in Creatinine do not mean much unless they are part of a trend. Sometimes you need to repeat the test to be sure.

A problem with Creatinine tests is that levels do not rise much in early kidney disease, they

Home Ne

← Back to R

Showing R

72 mi

Comments

There are no a

Zoom 1m



1. Jan. 2008 1. Jan. 2009 1. Jan. 2010 1. Jul. 2011 1. Jan. 2013 1. Jul. 2014



01-Feb-2012 16:35	64	Edin
14-Nov-2011 11:30	69	Edin
22-Sep-2011 12:15	62	Edin
06-Jul-2011 14:15	65	Edin

[Home](#)[News](#)[My Details](#)[My Conditions](#)[Results](#)[Medicines](#)[Letters](#)[Contact](#)

# Results Table View

[Back to Results](#)

To add more results to the table, select the result code from the dropdown. To remove them, click on 'x' next to the result label in the filter.

Your result selection will be saved for your next log in.

**Include Result Type:**

Please Select..

Urea



eGFR



Bili



Hb



Creatinine



Potassium



Date	Urea	eGFR	Bili	Hb	Creatinine	Potassium
16-Jan-2015 15:00				139		
02-Oct-2014 11:00	3.7		10	147	72	4.0
25-Jun-2014 10:50	3.6		6	138	69	4.6
09-Jan-2014 17:30	3.3		8	140	70	3.9
01-Oct-2013 12:30	3.7	116	8	139	66	4.7
13-Jun-2013 10:10	4.8	107.9	5	146	69	4.4
11-Apr-2013 13:00	3.3		9	148	69	4.1
10-Jan-2013 13:30	3.6		10	148	76	4.7
22-Aug-2012 14:15	3.8		9	135	68	4.5
19-Jun-2012 11:25	3.9		5	142	65	4.7
22-Apr-2012 16:15	4		7	144	67	4.8
01-Feb-2012 16:35	3.5		6	135	64	4.7
14-Nov-2011 11:30	3.7		7	141	69	4.6
22-Sep-2011 12:15	3.6		11	138	62	4.7

## Messages

Create New

Click on **View Messages** to see the full conversation or **Quick Reply** to reply to it. To send a new message, click on **Create New** above. When you send a message, the recipient will receive an email asking them to log in to read it, if they have an email address in the system.

Before sending your first message, check that we have the right email address for you in [Settings](#)

New

**test**

with: Nadim Yazdani

[Most recent message from: Nadim Yazdani](#)

test

22-Jan-2015 15:43

View Messages  
**1**

Quick Reply

**Emails from PatientView**

with: Neil Turner (Consultant)

[Most recent message from: andrew TURNER](#)

Replying now - not sure I got a flag or an email for this

22-Jan-2015 15:38

View Messages  
**2**

Quick Reply

**Comments about PatientView for the system administrators**

with: Klavs Zarins (Renal IT sysadmin)

[Most recent message from: andrew TURNER](#)

Neil testing this mechanism.

21-Jan-2015 07:13

Patient Support

View Messages  
**1**

Quick Reply



**PatientView  
centres**

**65 of 73 adult  
renal units**

**Over 43,000  
registrations**

## RaDaR

Welcome to the homepage of the UK Registry for Rare Kidney Diseases (RaDaR).

RaDaR is where healthcare professionals register patients and enter data.

Go to [RareRenal.org](http://RareRenal.org) for a list of diagnoses and check that your patient is eligible for the registry.

If you need patient information sheets and consent forms you can find them [here](#).

You can then log-in to RaDaR as a RaDaR/RPV Administrator. If this is your first visit you will need

to [register as a user](#).



# Alport's in Radar

Shows info on everyone to:

- Learn more
- Keep them and their docs up to date
- Spot those who may be suitable for
  - New treatments
  - New studies

# Thank you!

**Neil Turner**

neil.turner@ed.ac.uk

www.edren.org

