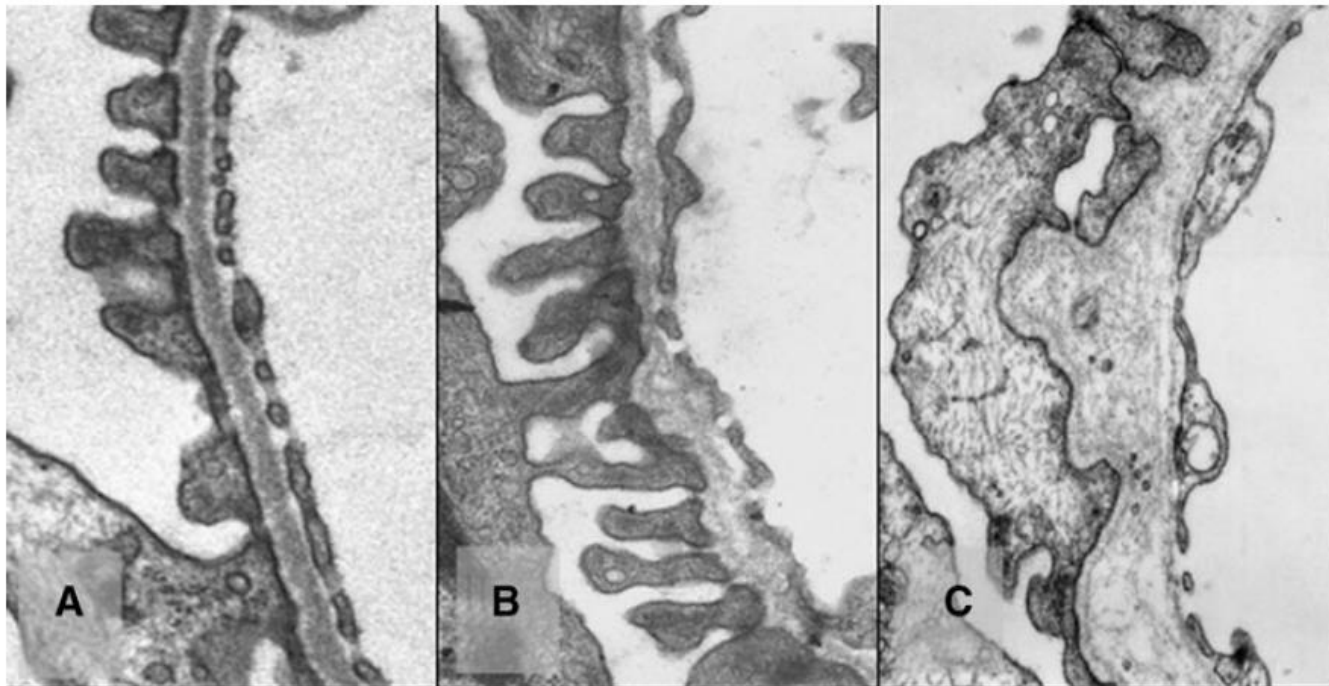


Research and Registries

Neil Turner





5th International Alport Workshop, Oxford Jan 2014



6th International Alport Workshop, Göttingen Sep 2015

Baumkuchen
 - mit Edelbitterschokolade -
 Die Spezialität unserer Konditoren

ca. 280 g	€ 11,50	(100g x 11,50)
ca. 440 g	€ 18,10	(100g x 11,50)
ca. 600 g	€ 24,00	(100g x 11,50)
ca. 900 g	€ 33,75	(100g x 11,50)

Konditorei und Café seit 1874



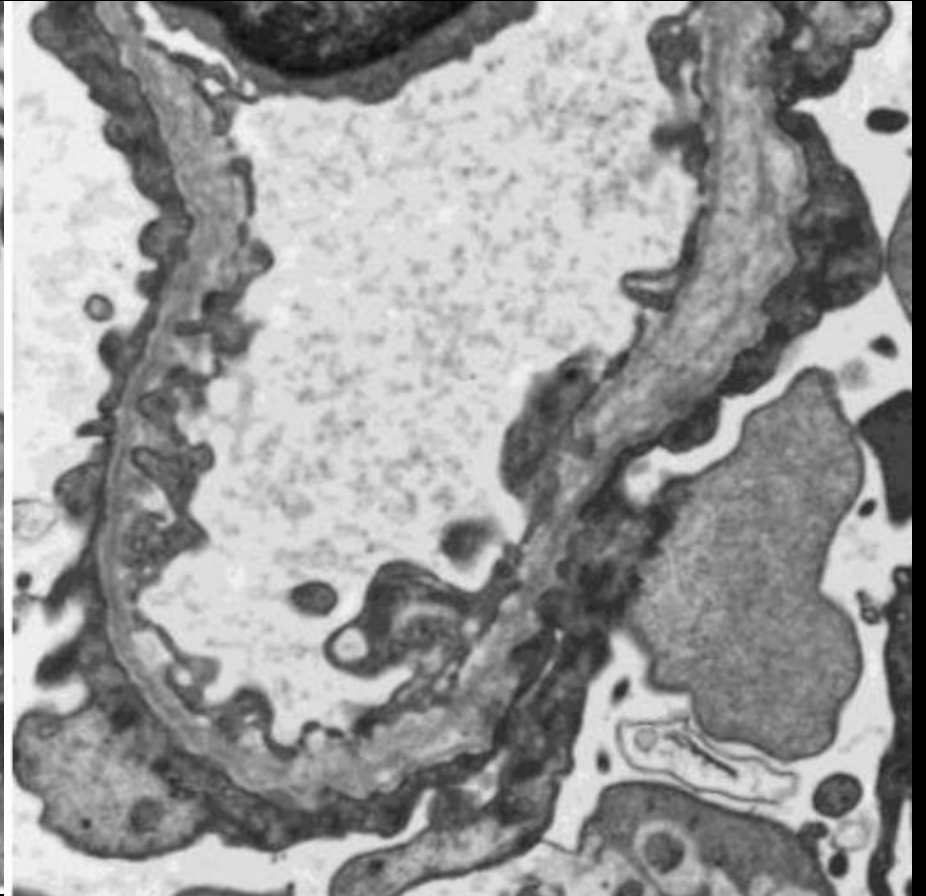
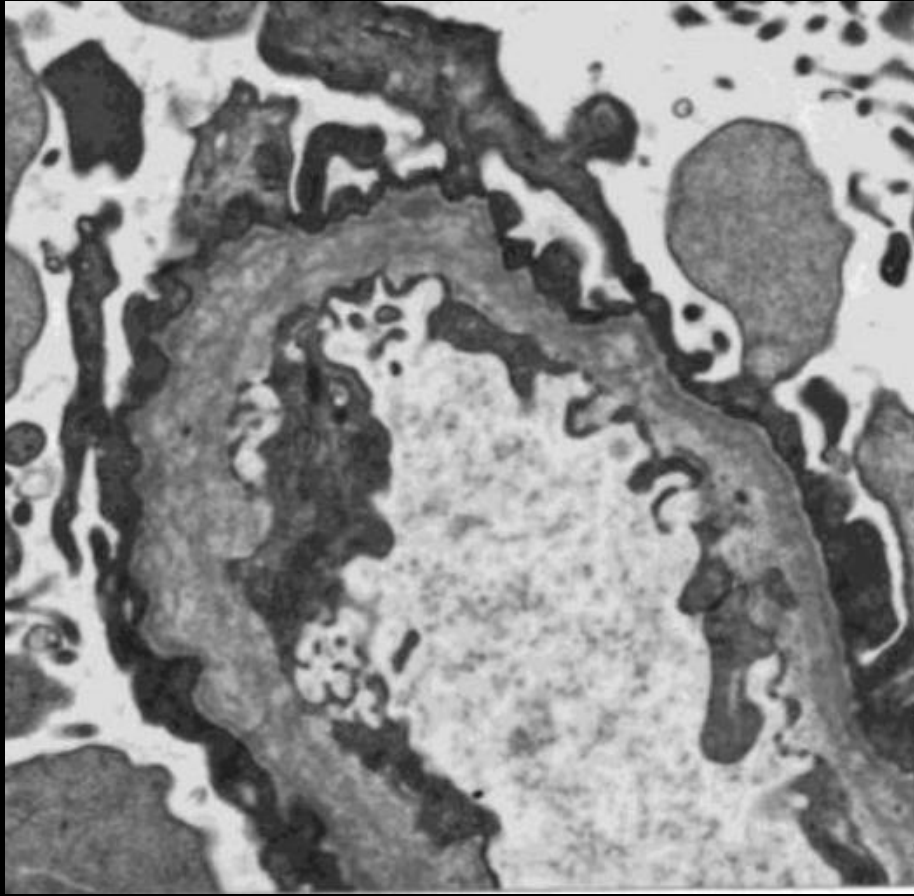
Amandebanankuchentorte
 mit Kaviarcreme
 € 9,50



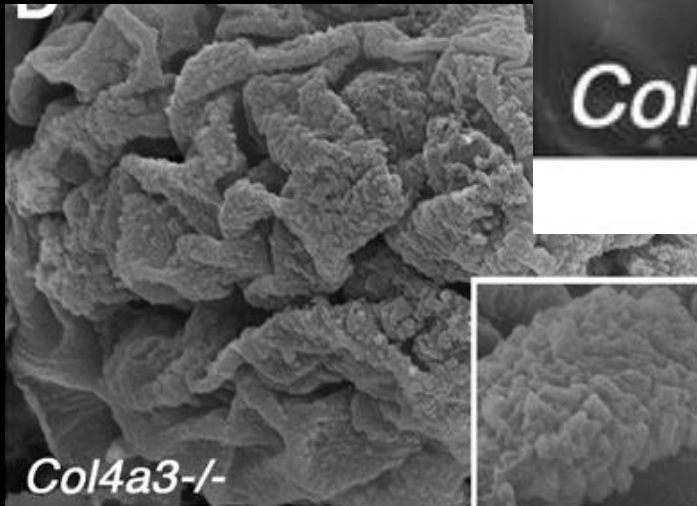
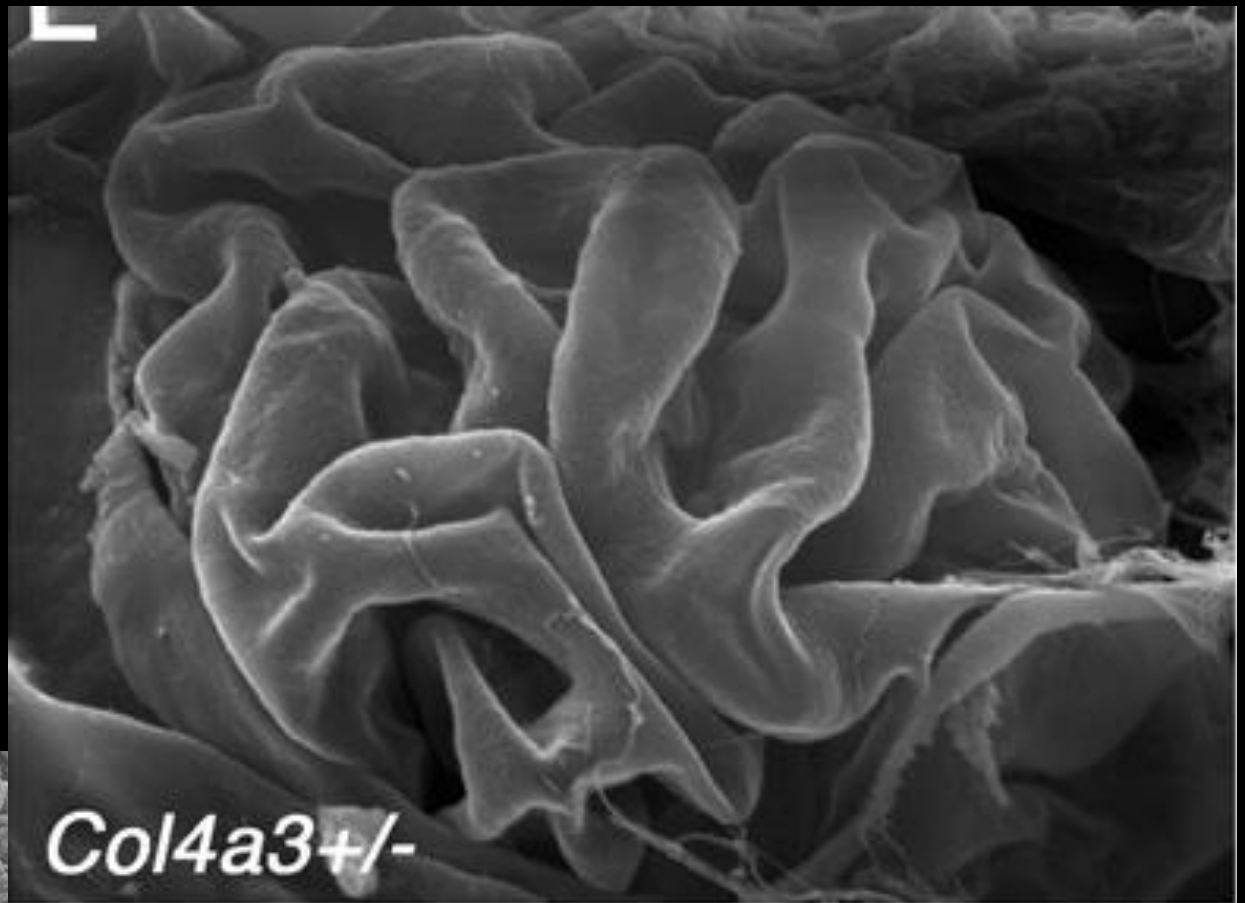
Flecker-Torte
 Erdbeere gebackt mit Orange
 € 13,-
 100g/100g



Florentiner
 Mandel & Feigen mit Sahnecreme von ALB
 20 Stk. € 2,-



Heidet 2014



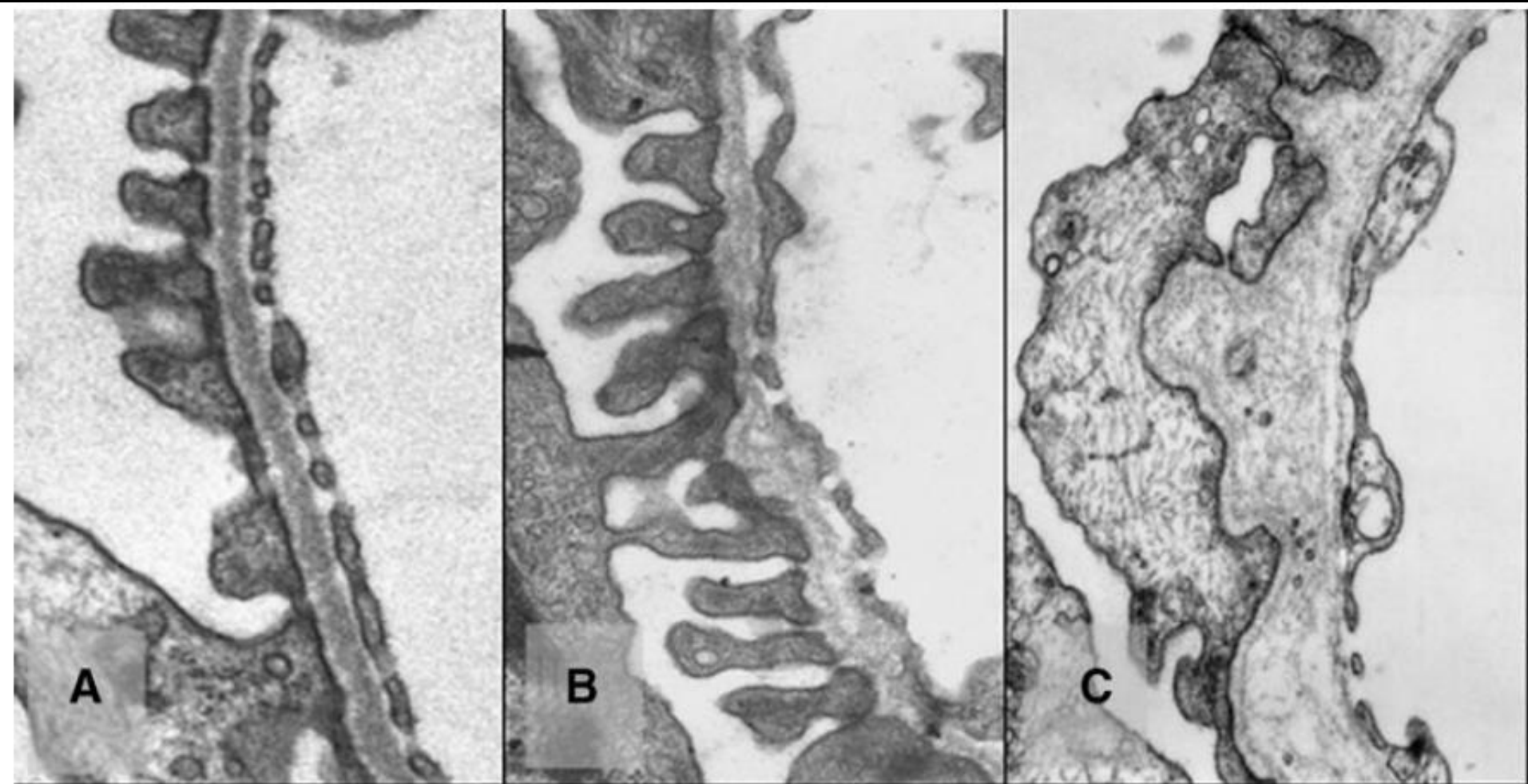
Lin, Miner 2014



6th International Alport Workshop, Göttingen Sep 2015

Some important research Qs

- Can we prevent kidney failure?
- Can we prevent deafness?
- What makes some carriers get severe disease?
- Will gene therapy ever be possible?



ACE inhibitors

- Slow down but don't stop
- There are already candidate drugs
 - Lower proteinuria?
 - Reduce scarring?
 - Stabilise GBM?

ACE inhibitors now

Anyone with proteinuria

- ‘Carrier’ or fully affected

Gene therapy?

Gene therapy?

Maybe one day

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

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

To find the next drug ...

Get registered?

RADAR

The problem with rare diseases

- Doctors don't know about them
- You don't know anyone else with them
- It's hard to find reliable info
- For staff as well as patients

and more ...

- Things keep changing
- Quality of care is patchy

Alport 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
- Place for expert advice

The Alport RDG

- 3 patients
- 2 adult nephrologists
- 2 paediatric nephrologists
- Geneticist
- Trials expert



Manage

your conditions and medications



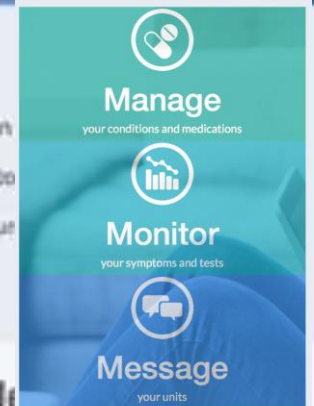
Monitor

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

Home

News

My Details

My Conditions

Results

Medicines

Letters

Contact

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

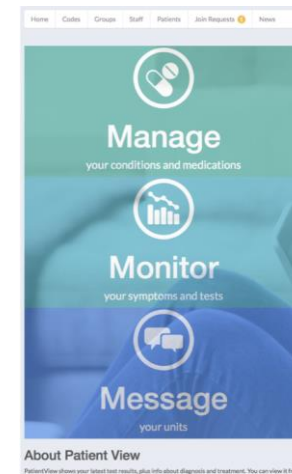
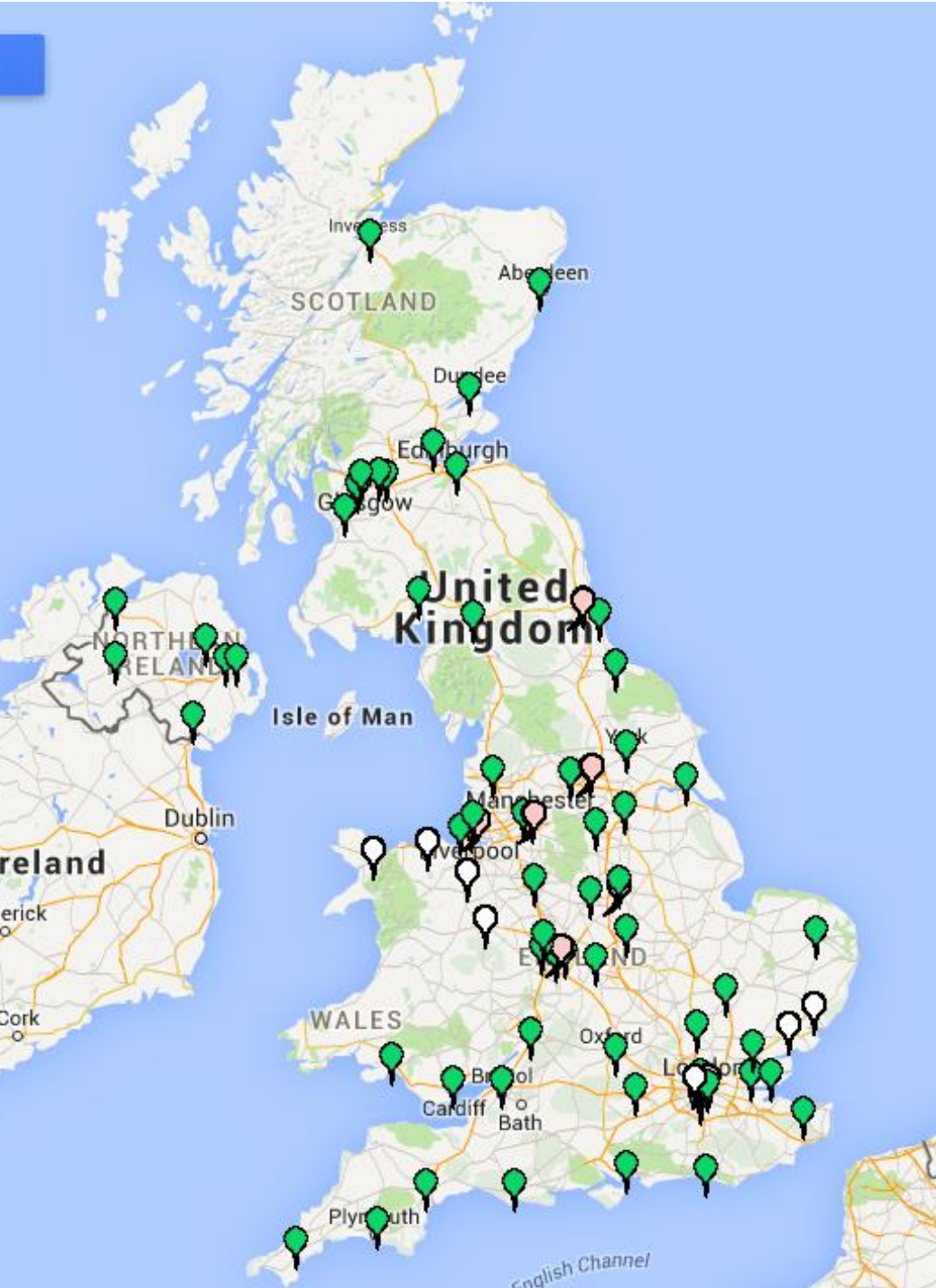
About

139 g/l

WBC

About

6.4



PatientView renal registrations

- **45,000** June 2015
- In **66** adult units
- Available to 90% adult population

Thank you!

Neil Turner

neil.turner@ed.ac.uk

www.edren.org

