ISTITUTO DI RICERCHE FARMACOLOGICHE MARIO NEGRI · IRCCS

Centro di Ricerche Cliniche per le Malattie Rare "Aldo e Cele Daccò"
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STEROID-RESISTANT NEPHROTIC SYNDROME (SRNS)

Registration Form

Referring Physician

Date of samples collection

Surname

Name

Hospital Address

Telephone Number

Fax Number

Email

Patient Data

Country

Surname

Name

Patient Sex

Birth Date

Birth Place

Is patient living?

If NO, date of death:

Address

telephone

mobile phone

e-mail

Codice fiscale (for italian resident only)

Tessera sanitaria (for italian resident only)

Family

ISS code

Patient Code (please leave blank)

Data at the 1st Kidney Biopsy

Referring Hospital for the Biopsy

Date

Serum Creatinine (mg/dl)

Height (cm)

Weight (Kg)

Other relevant features

Serum Albumin (g/dl)

Proteinuria (g/24h or P/C)

Serum Cholesterol (mg/dl)

Hematuria

- ☐ No
- ☐ Micro
- ☐ Gross

Blood pressure

Renal Biopsy (Please, provide a detailed description or attach a copy of the kidney biopsy report)

Number of glomeruli studied in the light microscopy

Light microscopy and Immunofluorescence

Electron microscopy

	Yes/No
At least 1 glomerulus with segmental or global collapse and overlying podocyte hypertrophy and hyperplasia.	
At least 1 segmental lesion involving the tip domain (presence of adhesion or confluence of podocytes with parietal or tubular cells at the tubular lumen or neck).	
At least 1 glomerulus with segmental endocapillary hypercellularity occluding lumina.	
More than 50% of glomeruli with segmental lesions have perihilar sclerosis or hyalinosis, of which at least 1 glomerulus with perihilar hyalinosis (with or without sclerosis)	
At least 1 glomerulus with segmental increase in matrix obliterating the capillary lumina.	

Note (please, record any other biopsies)

Please, fill the DATE of the 1st observation of the following events
(please, use approximate date o year only when the precise date is unknown):

First sign symptom | Proteinuria | Nephrotic syndrome | Microhematuria | Gross Hematuria

Chronic Renal Failure | End Stage Renal Disease (ESRD) | Hypertension | Hypercholesterolemia | Edema

Note

Data at the 1st sign of Kidney Disease

Date | Serum creatinine (mg/dl) | Height (cm) | Weight (kg) | Other relevant features

Serum Albumin (g/dl) | Proteinuria (g/24h or P/C) | Serum Cholesterol (mg/dl) | Hematuria: ☐ No ☐ Micro ☐ Gross

Blood pressure

Data at follow-up 1

Date | Serum creatinine (mg/dl) | Height (cm) | Weight (kg) | Other relevant features

Serum Albumin (g/dl) | Proteinuria (g/24h or P/C) | Serum Cholesterol (mg/dl) | Hematuria: ☐ No ☐ Micro ☐ Gross

Blood pressure

Data at follow-up 2

Date | Serum creatinine (mg/dl) | Height (cm) | Weight (kg) | Other relevant features

Serum Albumin (g/dl) | Proteinuria (g/24h or P/C) | Serum Cholesterol (mg/dl) | Hematuria: ☐ No ☐ Micro ☐ Gross

Blood pressure

Data at follow-up 3

Date | Serum creatinine (mg/dl) | Height (cm) | Weight (kg) | Other relevant features

Serum Albumin (g/dl) | Proteinuria (g/24h or P/C) | Serum Cholesterol (mg/dl) | Hematuria: ☐ No ☐ Micro ☐ Gross

Blood pressure

Clinical Data Recording (at the time of samples collection)

Date	Serum Creatinine (mg/dl)	Height (cm)	Weight (Kg)	Other relevant features

Serum Albumin (g/dl)	Proteinuria (g/24h or P/C)	Serum Cholesterol (mg/dl)	Hematuria
			☐ No ☐ Micro ☐ Gross

Blood pressure

Associated features :

	Yes/No
Diabetes	
Obesity (Body Mass Index)	
Infectious diseases (HIV, HBV, HCV etc.)	
Autoimmune diseases (SLE, thyroiditis, celiac disease, etc.)	
Cancer	
Deafness	
Ocular abnormalities	
Genital abnormalities (cryptorchidism etc.)	

Please specify the type of the feature or other features:

Dialysis and transplantation:

	Yes/No	Start at (Date): / Date
Peritoneal Dialysis		
Hemodialysis		Start at (Date):
Renal Transplantation		Date
Transplantation Failure		

Reasons for Transplantation Failure

Date of Return to Chronic Dialysis

	Yes/No	Date
Other Renal Transplantation		

Note

Primitive Nephropathy Treatment:

	Yes/No	Agent/ Dosage	Date of beginning	Date of suspension	Remission (CR/PR/NR)	Relapse
Corticosteroid						
Cyclophosphamide						
Cyclosporine						
Mycophenolate Mofetil						
Angiotensin Converting Enzyme (ACE) inhibitors						
Angiotensin Receptor Blockers (ARBs)						
Statin						
Rituximab						

More information on the above treatments, other treatments and notes

Family History

	Yes/No
Consanguinity of parents:	

	Yes/No
Family history for Renal Diseases:	

If YES, specify if there are family members with:

	Yes/No
Renal biopsy demonstrating FSGS, without evidence of other systemic diseases causing FSGS	
ESRD/Dialysis	
Renal Transplantation	
Proteinuria/Nephrotic Syndrome	
Chronic Renal Failure	

Family history for other diseases:

Please, specify if there are family members with:

	Yes/No
Autoimmune diseases	
Diabetes	
Cancer	
Deafness	
Other (please, specify)	

Note (Please, list the relation and the type of the disease)

Please if there is a family history draw the pedigree

I

I I

III

IV

Please point out the proband with an arrow

Please affix a progressive number to each component of each generation

Family History Identification of the Family Members:

	Name and Surname	Bx_Note Other biopsies
I1		
I2		
I3		
...		
...		
...		
...		
...		
...		
...		
...		
...		
...		
...		
...		
...		

If one of the family members is affected, please compile a new registration form!

Note