MALAYSIA RARE KIDNEY DISEASE REGISTRY (MaRKiD) | NOTIFICATION FORM

Instruction: Where check boxes ☐ are provided, check (√) one or more boxes. Where radio buttons ○ are provided, check (√) one box only.
** indicates compulsory field.*

1.	*Name of hospital		
2.	*Date of notification	__ __ / __ __ / __ __ __ __ *(dd/mm/yyyy) (Auto)*	
3.	* MaRKid Patient ID	__ __ __ __ __ __ - __ __ __ __	*(This is an auto generated ID after registering patient in system. Please copy the ID to your centre's Subject Enrolment Log)*
4.	* MRRB ID	(Auto if patient exists in MRRB during IC search)	

A. PATIENT DEMOGRAPHICS *Instruction: Please keep the patient's identifier at local level for future reference.*

1.	*Patient initial	__ __ __ __		
2.	Last 6 digit ID number	__ __ __ __ __ __ (For Malaysian, last 6 digit of IC number; For Non Malaysian, last 6 digit of Passport/ ID number)		
3.	*a. Date of birth	__ __ / __ __/ __ __ __ __ *(dd/mm/yyyy)*	*b. Age at notification	__ __ __ years old *(Auto)*
4.	*Gender	○ Male	○ Female	
5.	*Ethnicity	○ Malay ○ Other M'sian, specify: _____	○ Chinese ○ Foreigner, specify: _____	○ Indian
6.	*Biopsy?	○ Biopsy →	i. Date of biopsy:	__ __ / __ __/ __ __ __ __ *(dd/mm/yyyy)*
		○ Not Biopsy		

7. *Name of disease *(Select main and sub category a to f)*

(Patients with diseases in blue font will be auto from MRRB if registered before)

○ 1. Genetic disorders →	○ 101. Autosomal Dominant Polycystic Kidney Disease (ADPKD) ○ 102. Autosomal Recessive Polycystic Kidney Disease ○ 103. Alport's Syndrome ○ 104. Fabry's Disease ○ 105. Thin Basement Membrane Disease ○ 106. Congenital Nephrotic Syndrome ○ 107. APOL 1 – Mediated Kidney Disease ○ 108. Tuberous Sclerosis Complex ○ 199. Other genetic disorder, specify: _____
○ 2. Structural abnormalities →	○ 201. Congenital Abnormalities of the Kidneys and Urinary Tract (CAKUT) ○ 202. Nephronophtosis ○ 203. Cystic Kidney Disease ○ 299. Other structural abnormalities, specify: _____
○ 3. Metabolic disorders →	○ 301. Cystinosis ○ 302. Oxalosis ○ 399. Other metabolic disorders , specify: _____
○ 4. Glomerular disease →	○ 401. IgA Nephropathy ○ 402. Henoch Schonlein Purpura ○ 403. Membranoproliferative GN ○ 404. C3 Glomerulopathy (C3G) ○ 405. Focal Segmental Glomerulosclerosis (FSGS) ○ 406. Minimal Change Disease ○ 407. ANCA-associated Vasculitis ○ 408. Anti-Glomerular Basement Membrane Disease ○ 409. Lupus Nephritis ○ 411. Membranous nephropathy ○ 499. Other glomerular disease, specify: _____
○ 5. Tubular disease →	○ 501. Gitelman Syndrome ○ 502. Bartter Syndrome ○ 599. Other tubular disease, specify: _____

		○ 6. Thrombotic microangiopathy (TMA) →	○ 601. STEC - HUS ○ 602. Thrombocytopenia Purpura (TTP) ○ 603. Complement-mediated aHUS ○ 604. Triggering factors ○ 6041. Other Infection, specify: _____ ○ 6042. Malignancy ○ 6043. Pregnancy ○ 6044. Malignant hypertension ○ 6045. Autoimmune diseases ○ 6046. Transplant ○ 6047. Drug ○ 6048. Metabolic ○ 6049. No identifiable trigger
		○ 7. Miscellaneous →	○ 701. Calcific Uremic Arteriolopathy (CUA) ○ 799. Others, specify: _____

Instruction: If item 7.1 / 7.2 / 7.3 / 7.4 / 7.5 / 7.6 / (7.7 = 799 Others), proceed to 8, 9 and 10 below.
If item 7.1 = 101 ADPKD, proceed to 8, 9, 10 and 11 below.
If item 7.7 = 701 CUA, proceed to 8, 10 and 12 below.

8.	***CKD / ESKD**	○ **a. Chronic Kidney Disease Stage (non dialysed CKD/ESKD)** →	**i. Serum Creatinine**	_____ ○ µmol/L ○ mg/dL	_____ µmol/L *(Auto)*
			ii. eGFR *(Auto)*	_____ mL/min/1.73m² *(Auto)*	
		○ **c. Transplanted** →	**iii. CKD Stage** *(Auto)*	○ Stage 1 ○ Stage 2 ○ Stage 3a ○ Stage 3b ○ Stage 4 ○ Stage 5	
		○ **b. End Stage Kidney Disease (ESKD)** →	**i. Modality**	○ HD ○ PD ○ Transplant	
9.	***Proteinuria / Albuminuria (for CKD)**	**a. Urine PCI/PCR**	_____ ○ mg/mg ○ mg/g ○ mg/mmol ○ g/mmol _____ mg/mmol *(Auto)*	☐ Not available	
		b. Urine ACR	_____ ○ mg/mg ○ mg/g ○ mg/mmol ○ g/mmol _____ mg/mmol *(Auto)*	☐ Not available	
10.	***Genetic testing**	○ Yes	○ No	○ Not relevant	
11.	***If ADPKD:**	**a. Imaging:**	○ CT	○ MRI	○ Not available
		b. Mayo class (If Imaging = CT/MRI)	○ 1A ○ 1B ○ 1C ○ 1D ○ 1E ○ Not done		
12.	***If Calcific Uremic Arteriolopathy (CUA):**	**a. Skin biopsy:**	○ Yes →	**i. Date of biopsy:**	__ __ / __ __ / __ __ __ __ *(dd/mm/yyyy)*
			○ No		
		b. Diabetes Mellitus (DM):	○ Yes	○ No	
		c. Site of lesions:	○ Periphery (limbs)	○ Central (trunk / buttocks / thighs)	○ Both