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ERN eUROGEN

**European Reference Network for rare urogenital
diseases and complex conditions**

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Authors:	Jen Tidman, ERN eUROGEN Business Support Manager
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1. DISSEMINATION RESULTS

1.1. Strategic Objective during the Bridging Grant

During the Bridging Grant (1 March 2022 - 30 September 2023), ERN eUROGEN has successfully disseminated knowledge across the enlarged network and beyond through active cross-ERN, EU, and international collaborations, providing updates of public and network information through the ERN eUROGEN website, YouTube channel and additional social media platforms. Evidence of this can be seen below relating to the indicators.

1.2. Indicators during the Bridging Grant

Impact/Outcome Indicator No	Impact/Outcome Indicator Name	Target Value	Due Date
WP2.PI1	Dissemination activities further developed	Increased website hits, newsletter, and YouTube/social media subscribers, sending out at least 10 -newsletters	M18

During the grant, ERN further developed its dissemination activities. Website hits increased (see WP2.112 below). [16 main e-newsletters](#) were sent, and newsletter subscribers increased (Mailchimp analytic data does not go back further than 365 days, but there were 909 new subscribers from 17 September 2022 to 18 September 2023). Subscribers also increased for the ERN eUROGEN YouTube channel and other social media platforms:

		YouTube new subscribers	X (Twitter) new followers	Facebook new followers	Instagram new followers	LinkedIn new followers
Q1 2022	Mar/22	18	34	6	10	13
	Apr/22	18	16	5	16	11
	May/22	21	28	6	24	23
Q2 2022	Jun/22	29	17	7	21	17
	Jul/22	22	44	12	23	23
	Aug/22	7	5	0	4	6
Q3 2022	Sep/22	44	22	6	8	21
	Oct/22	33	11	4	14	17

	Nov/22	11	1	4	7	20
Q4 2022	Dec/22	9	13	3	11	16
	Jan/23	8	13	2	12	32
	Feb/23	15	15	4	16	17
Q1 2023	Mar/23	53	18	5	22	18
	Apr/23	12	8	2	15	9
	May/23	14	8	5	10	13
Q2 2023	Jun/23	21	13	2	17	6
	Jul/23	21	4	7	3	14
	Aug/23	5	0	2	9	0
Increase during grant		361	270	82	242	276
Total followers		695	1135	176	539	447

WP2.PI2	Global collaboration	Two additional signed global collaboration agreements when applicable	M18
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The target was met and exceeded, and ERN eUROGEN now has three global [Collaborative Partners](#):

1. Since March 2022, a Memorandum of Understanding (MoU) has been signed and in place between ERN eUROGEN and [CureForU](#) relating to dynamic collaborative networks of Western & Eastern Medical experts.
2. Since April 2022, a Memorandum of Understanding (MoU) has been signed and in place between ERN eUROGEN and the [Murdoch Children's Research Institute](#) in Melbourne, AU, to form a uro-recto-genital collaborative working group on anorectal malformation (ARM) innovations.
3. Since May 2023, a Memorandum of Understanding (MoU) has been signed and in place between ERN eUROGEN and the [Confederación Americana de Urología](#) (CAU) to collaborate on penile cancer.

WP2.011	Dissemination activities for webinar programme increased with Supporting Partners	Increase registrations to webinars by 20%	M18
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E-newsletters were sent out to ERN eUROGEN 's stakeholders when webinar registration opened, and these were shared with the network's [Supporting Partners](#), who were also tagged in social media posts promoting the webinars, so that they could easily share these through their dissemination channels. During the 18 months preceding the grant (September 2020 to February 2022) there was a mean of 133 webinar registrants, therefore a 20% increase gave a target of 160 registrants. This target was met exactly, with an average of 160 registrants over the grant period.

WP2.012	Prepare representation at Annual European Association of Urology (EAU) Congress (planned 1-4 July 2022 Amsterdam)	Potential to reach audience of 18,000 urologists. Preparation of one ERN EUROGEN Special Session. Preparation of one CPMS helpdesk at the congress	M7
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ERN eUROGEN actually had a presence at two EAU congresses, from 1-4 July 2022 in Amsterdam and 10-13 March 2023 in Milan. The network prepared a thematic (special) session at each congress (see WP2.013 below for details) and had a CPMS helpdesk in the exhibition centre at both congresses.

WP2.013	Number of congresses / conferences / meetings at which the ERN activities and results are presented	At least 5 new events at which ERN activities & results are presented by M18	M18
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The target was met and exceeded:

Date	Congress/Conference/Meeting	Presenter(s)	HCP	Title
23-Mar	EUPSA WebSeminar	Wout Feitz & Ivo de Blaauw	NL-Radboud	Cloacal Exstrophy
23-Apr	KINDERUROLOGISCHES LECHSYMPOSIUM 2022	Wout Feitz	NL-Radboud	COMPETITION OR COLLABORATION. What is The Best for The Future. Share, Care, Cure (EU4Health)
07-May	Turkish National Endourology Congress	Hans Langenhuijsen	NL-Radboud	Posterior laparoscopic adrenalectomy, indications, equipment, technique, and results.
25-May	Workshop on the Global Rare Diseases Network	Michelle Batty	NL	Strengthening National Healthcare Systems: Learning from the Clinical Patient Management System
08-Jun	European Society for Paediatric Urology Nurses (ESPUN) annual meeting	Wout Feitz	NL-Radboud	ERN eUROGEN Update 2022: Multidimensional expansion and expertise involvement
09-Jun	European Society for Paediatric Urology (ESPU) annual meeting	Wout Feitz	NL-Radboud	ERN eUROGEN Update
22-Jun	European Rare Disease Research Coordination and Support Action consortium (ERICA) annual meeting	Jorgen Thorup	DK-Copenhagen	Pharmaceutical study with cryptorchidism
		Loes van der Zanden	NL-Radboud	GWAS identifies CDH12 as candidate gene for kidney injury in posterior urethral valves
27-Jun	European Conference on Rare Diseases	Michelle Batty	NL-Radboud	European Region Readiness for the CGN for RD Pilot
03-Jul	European Association of Urology congress (EAU22) - ERN eUROGEN Thematic Session	Michelle Batty	NL-Radboud	Update on ERN eUROGEN developments
		Rob Cornes, John Osborne, Kenneth Manzie	UK	ERN Patient Advocacy Group (ePAG) lecture Penile cancer: The way forward?
		Giovanni Mosiello	IT-Rome BG	Workstream 1 (rare congenital uro-recto-genital anomalies) lecture Congenital neurogenic bladder dysfunction: What the adult urologist needs to know
		Mariangela Mancini	IT-Padova	Workstream 2 (functional urogenital conditions requiring highly specialised surgery) lecture Vesico-vaginal fistula: Management strategies and keys to successful treatment

		Hans Langenhuijsen	NL-Radboud	Workstream 3 (rare urogenital tumours) lecture Expansion of the network with tremendous opportunities for rare urogenital tumours
		Magdalena Fossum	SE-Stockholm	The COVID-19 pandemic Patient impact in 10 European centers for uro-rectogenital care
24-Aug	KV22	Nikolai Juul	DK-Copenhagen	How the first year of COVID-19 affected elective pediatric urology patients:
09-Sep	National Organisation for Rare Diseases of Serbia (NORBS) conference	Michelle Battye	NL-Radboud	ERN eUROGEN European Reference Network for rare urogenital diseases and complex conditions
23-Sep	Deutsche Gesellschaft für Urologie (DGU) meeting	Aybike Hofmann	DE-Regensburg	HOW THE FIRST YEAR OF COVID-19 AFFECTED ELECTIVE PEDIATRIC UROLOGY PATIENTS
13-Oct	WOFAPS (World Congress of Paediatric Surgery)	Nikolai Juul	DK-Copenhagen	How the first year of COVID-19 affected elective pediatric urology patients:
20-Oct	22nd Tunisian Urological Association (ATU)/Pan-African Urological Surgical Association (PAUSA) Congress	Hans Langenhuijsen	NL-Radboud	EAU Guideline recommendations and indications for adrenal surgery
				Transperitoneal adrenalectomy and metastatectomy
				Partial adrenalectomy and challenging cases
27-Nov	European Paediatric Surgeon's Association (EUPSA) Autumn Meeting	Wout Feitz	NL-Radboud	ERN eUROGEN 2022: Multidimensional Expansions
10-Feb	Final Meeting on ERN Exchange Programme	Jen Tidman	NL-Radboud	ERN Exchange Programme: Insight into ERN eUROGEN's Success Factors
17-Feb	Mediterranean Incontinence & Pelvic Floor Society	Emilio Sacco	IT-Rome Gemelli	Post-prostatectomy incontinence on behalf of eUROGEN - European Reference Network
28-Feb	Rare Diseases Malta Seminar	Michelle Battye	NL-Radboud	ERN eUROGEN Registry & Training Developments
10-Mar	European Association of Urology congress (EAU23) - Adrenals for urologists ESU Course	Hans Langenhuijsen	NL-Radboud	Indications and patient preparation (medical and surgical)
				How I do it, step by step operative procedure, technical tips and tricks - Transperitoneal
				Partial adrenalectomy and challenging cases in adrenalectomy
13-Mar		Michelle Battye	NL-Radboud	Update on ERN eUROGEN developments

	European Association of Urology congress (EAU23) - ERN eUROGEN Thematic Session	Rob Cornes	ePAG	The importance of communication in rare diseases & complex conditions: The patient perspective
		Ramon Gorter	NL-Amsterdam	Urogenital problems in rare and complex forms of anorectal malformation: Paediatric surgical, urological, & gynaecological perspectives
		Mariangela Mancini	IT-Padova	Interstitial cystitis: Current evidence, personal perspectives, ideas for the future
		Arnout Alberts	NL-Rotterdam	Testicular cancer: collaborative project between 2 eUROGEN expert centers
		Yue Che	DE-Dusseldorf	PRIMETEST II – trial to test new predictors of recurrence in CS II A/B seminoma patients treated with primary robot-assisted retroperitoneal lymph node dissection
		Peter-Paul Willemse	NL-Utrecht	Testicular cancer: collaborative project
	European Association of Urology congress (EAU23) - Rare and complex urology Abstract Session	Wout Feitz	NL-Radboud	ERN eUROGEN update 2023
	European Association of Urology congress (EAU23) - Latest scientific developments in male post-prostatectomy incontinence (PPI) Thematic Session	Frank Van Der Aa	BE-Leuven	Reflection on RCTs vs registries
31-Mar	United Kingdom Continence Society (UKCS) meeting	Frank Van Der Aa	BE-Leuven	Management of Mesh Complications: How to Remove Mesh
21-Apr	European Society for Paediatric Urology (ESPU) congress	Wout Feitz	NL-Radboud	ERN eUROGEN update 2023
21-Apr	EURORDIS Exchange of Good Practice webinar: Patient Representatives Involvement in the ERN Evaluation	Michelle Batty	NL-Radboud	ERN eUROGEN Patient Representatives Involvement in the ERN Evaluation
04-Jun	EJP RD Trans-ERN training workshop: Fetal and Postnatal multidisciplinary management in RD: Myelomeningocele and LUTO.	Wout Feitz	NL-Radboud	ERN eUROGEN Guideline developments and LUTO
04-Jun		Michelle Batty	NL-Radboud	Overview of ERN and trans ERN activities
13-Sep	Urological research meeting, Radboudumc	Loes Oomen	NL-Radboud	Pediatric Kidney Transplantation: A local, national and international perspective

WP2.014	Dissemination Plan updated	Document updated	M8
See Deliverable D2.3 for the details of the updated Dissemination Plan.			
WP2.015	Dissemination Report produced	Document produced	M10
This is the Dissemination Report.			
WP2.111	Increased awareness of ERN eUROGEN	5 new publications from the network	M18
<p>ERN eUROGEN has generated 7 new publications that are in PubMed-accredited scientific journals, involve as major contributors at least two healthcare providers (HCPs) from two different Member States within the ERN, and acknowledge the ERN:</p> <ol style="list-style-type: none"> Ashley S, Shilhan D, Battye M, Meyer C, Mancini M, Ayres B, Muneer A, Albersen M, Feitz W, Langenhuijsen JF, Sangar V. Clinical performance in ERN eUROGEN for penile, testicular, adrenal and soft tissue cancers. <i>Eur J Surg Oncol</i>. 2022 Mar;48(3):680-686. doi: 10.1016/j.ejso.2021.11.014. Juul N, Cazals A, Hofmann A, Amesty V, Verkauskas G, Dobrowolska-Glazar B, Holmdahl G, Escolino M, Birraux J, Kovacs T, Kalfa N, Fossum M. How the First Year of COVID-19 Affected Elective Pediatric Urology Patients: A Longitudinal Study Based on Waiting Lists and Surveys From 10 European Centers. <i>Front Public Health</i>. 2022 Apr 28;10:874758. doi: 10.3389/fpubh.2022.874758. Capone, V., Persico, N., Berrettini, A. <i>et al.</i> Definition, diagnosis and management of fetal lower urinary tract obstruction: consensus of the ERKNet CAKUT-Obstructive Uropathy Work Group. <i>Nat Rev Urol</i> 19, 295–303 (2022). doi: 10.1038/s41585-022-00563-8. Souche E, Beltran S, Brosens E, Belmont JW, Fossum M, Riess O, Gilissen C, Ardeshirdavani A, Houge G, van Gijn M, Clayton-Smith J, Synofzik M, de Leeuw N, Deans ZC, Dincer Y, Eck SH, van der Crabben S, Balasubramanian M, Graessner H, Sturm M, Firth H, Ferlini A, Nabbout R, De Baere E, Liehr T, Macek M, Matthijs G, Scheffer H, Bauer P, Yntema HG, Weiss MM. Recommendations for whole genome sequencing in diagnostics for rare diseases. <i>Eur J Hum Genet</i>. 2022 May 16. doi: 10.1038/s41431-022-01113-x. van der Zanden Loes F. M., Maj Carlo, Borisov Oleg, van Rooij Iris A. L. M., Quaedackers Josine S. L. T., Steffens Martijn, Schierbaum Luca, Schneider Sophia, Waffenschmidt Lea, Kiemeneij Lambertus A. L. M., de Wall Liesbeth L. L., Heilmann Stefanie, Hofmann Aybike, Gehlen Jan, Schumacher Johannes, Szczepanska Maria, Taranta-Janusz Katarzyna, Kroll Pawel, Krzemien Grazyna, Szmigielska Agnieszka, Schreuder Michiel F., Weber Stefanie, Zaniew Marcin, Roeleveld Nel, Reutter Heiko, Feitz Wout F. J., Hilger Alina C. Genome-wide association study in patients with posterior urethral valves. <i>Frontiers in Pediatrics</i>. 2022 Sep 27. doi: 10.3389/fped.2022.988374. Brouwer OR, Albersen M, Parnham A, Protzel C, Pettaway CA, Ayres B, Antunes-Lopes T, Barreto L, Campi R, Crook J, Fernández-Pello S, Greco I, van der Heijden MS, Johnstone PAS, Kailavasan M, Manzie K, Marcus JD, Necchi A, Oliveira P, Osborne J, Pagliaro LC, Garcia-Perdomo HA, Rumble RB, Sachdeva A, Sakalis VI, Zapala Ł, Sánchez Martínez DF, Spiess PE, Tagawa ST. European Association of Urology-American Society of Clinical Oncology Collaborative Guideline on Penile Cancer: 2023 Update. <i>Eur Urol</i>. 2023 Mar 7:S0302-2838(23)02638-6. Doi: 10.1016/j.eururo.2023.02.027. de Beaufort CMC, Aminoff D, de Blaauw I, Crétole C, Dingemann J, Durkin N, Feitz WFJ, Fruithof J, Grano C, Burgos CM, Schwarzer N, Slater G, Soyer T, Violani C, Wijnen R, de Coppi P, Gorter RR; Transition of Care study group. Transitional Care for Patients with Congenital Colorectal Diseases: An EUPSA Network Office, ERNICA, and eUROGEN Joint Venture. <i>J Pediatr Surg</i>. 2023 Jun 14:S0022-3468(23)00368-8. doi: 10.1016/j.jpedsurg.2023.06.008. <p>There have also been several additional publications that do not meet the reporting criteria, but which were generated by network experts relating to ERN eUROGEN 's Expertise Areas and therefore increase awareness and share knowledge. See the full list of publications here.</p>			
WP2.112	Number of individual ERN website hits	40,000 page views	M18
The target was met and exceeded:			
Q1 2022	Mar/22	2880	
	Apr/22	2098	

	May/22	2888
Q2 2022	Jun/22	2524
	Jul/22	2204
	Aug/22	2381
Q3 2022	Sep/22	2604
	Oct/22	3220
	Nov/22	3168
Q4 2022	Dec/22	3235
	Jan/23	2495
	Feb/23	2983
Q1 2023	Mar/23	3096
	Apr/23	2287
	May/23	2188
Q2 2023	Jun/23	2350
	Jul/23	2265
	Aug/23	2061
TOTAL		46927

WP2.113	Updated Dissemination Strategy agreed by Strategic Board	Dissemination Plan agreed by Strategic Board	M8
The Dissemination Plan (see Deliverable D2.3) was circulated to the ERN eUROGEN Strategic Board for approval in accordance with the network's Governance Statutes and no objections were received.			
WP2.114	Dissemination Report agreed by Strategic Board	Dissemination Plan agreed by Strategic Board	M10
This Dissemination Report was circulated to the ERN eUROGEN Strategic Board for approval in accordance with the network's Governance Statutes and no objections were received.			
WP2.115	Knowledge dissemination of healthcare professionals and patients	Increased knowledge of rare urogenital diseases and complex conditions	M18
We believe this has been achieved by the above activities.			