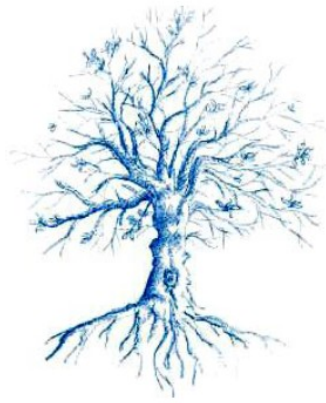
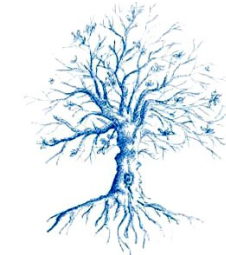


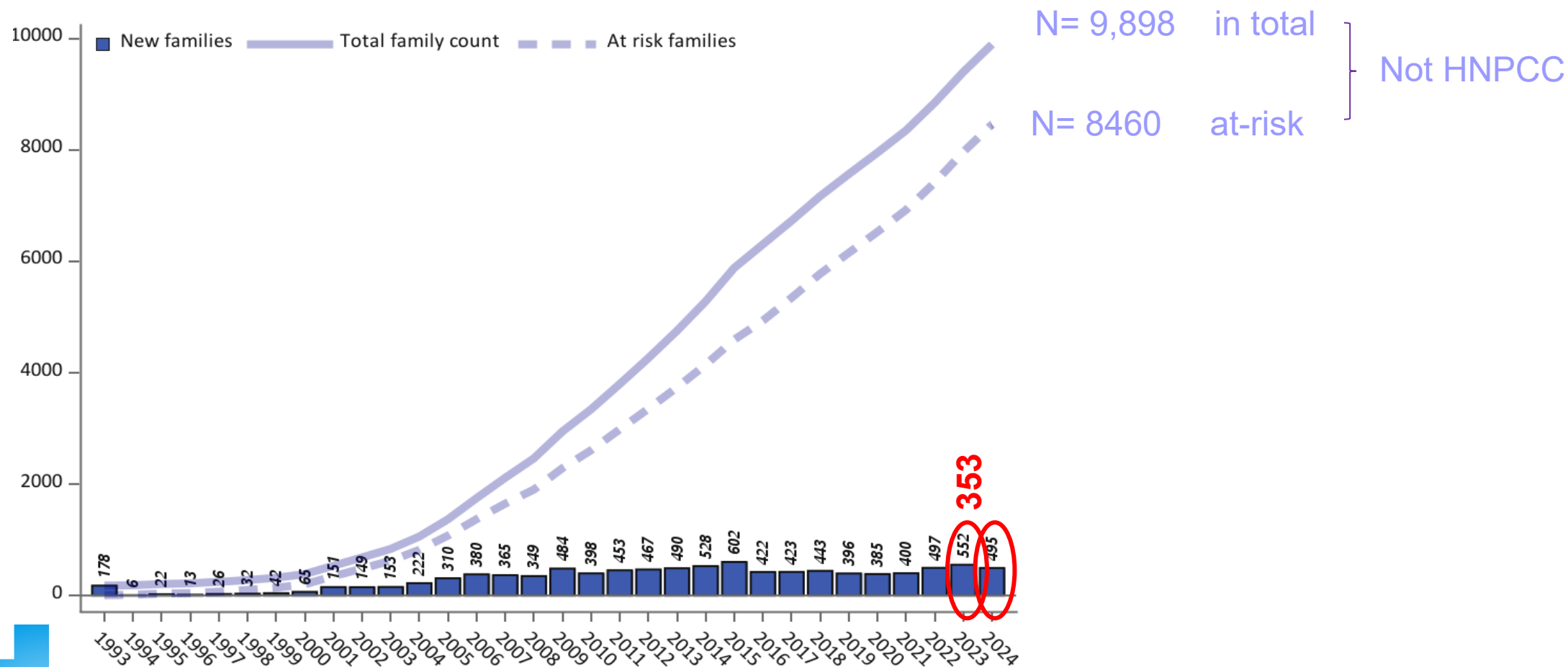


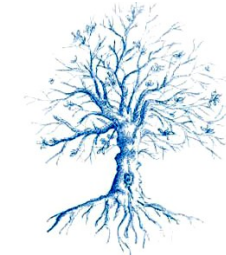
HNPCC Symposium 2025

Welcome and News



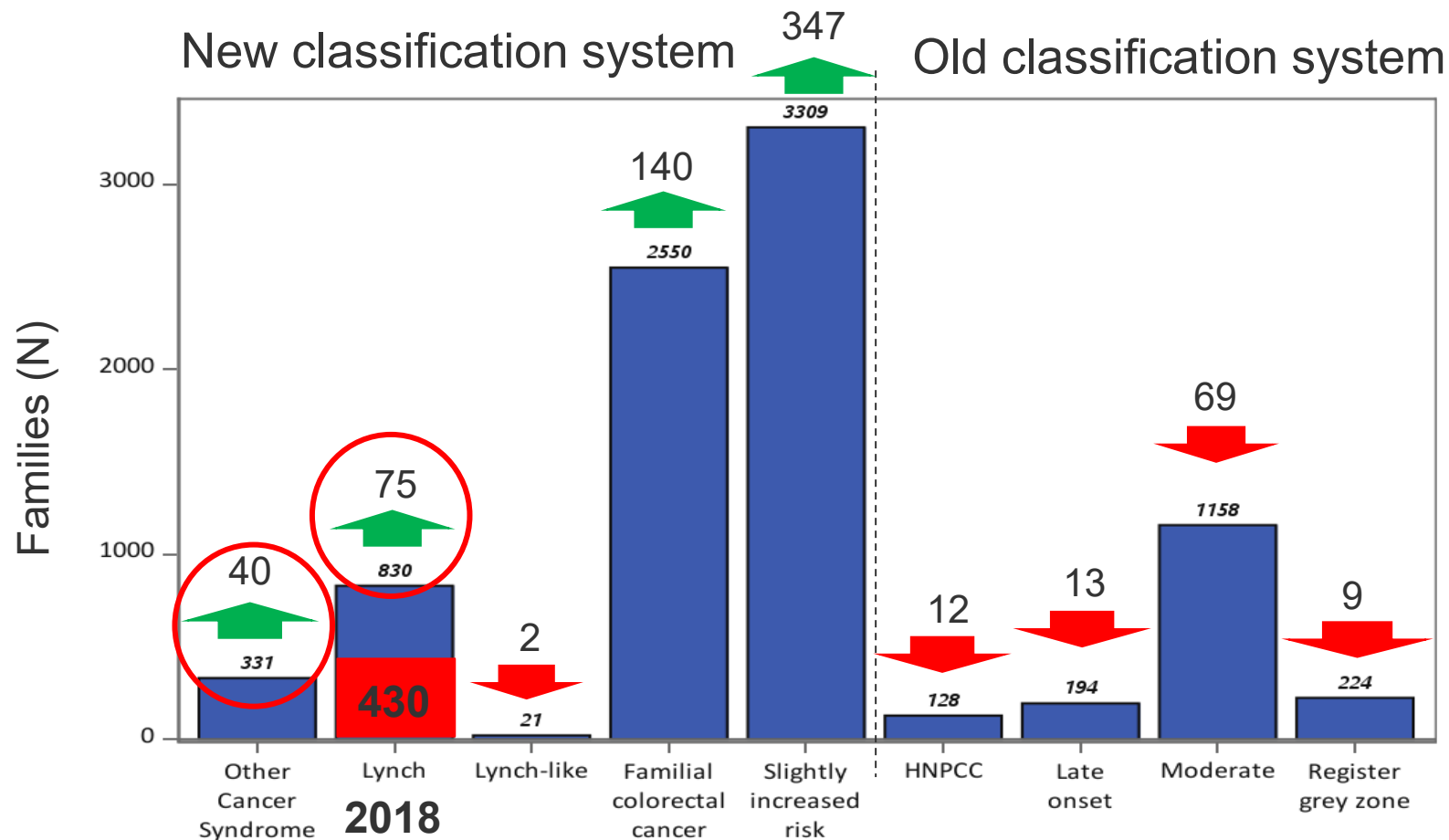
New families per year and in total (by Dec 2024)



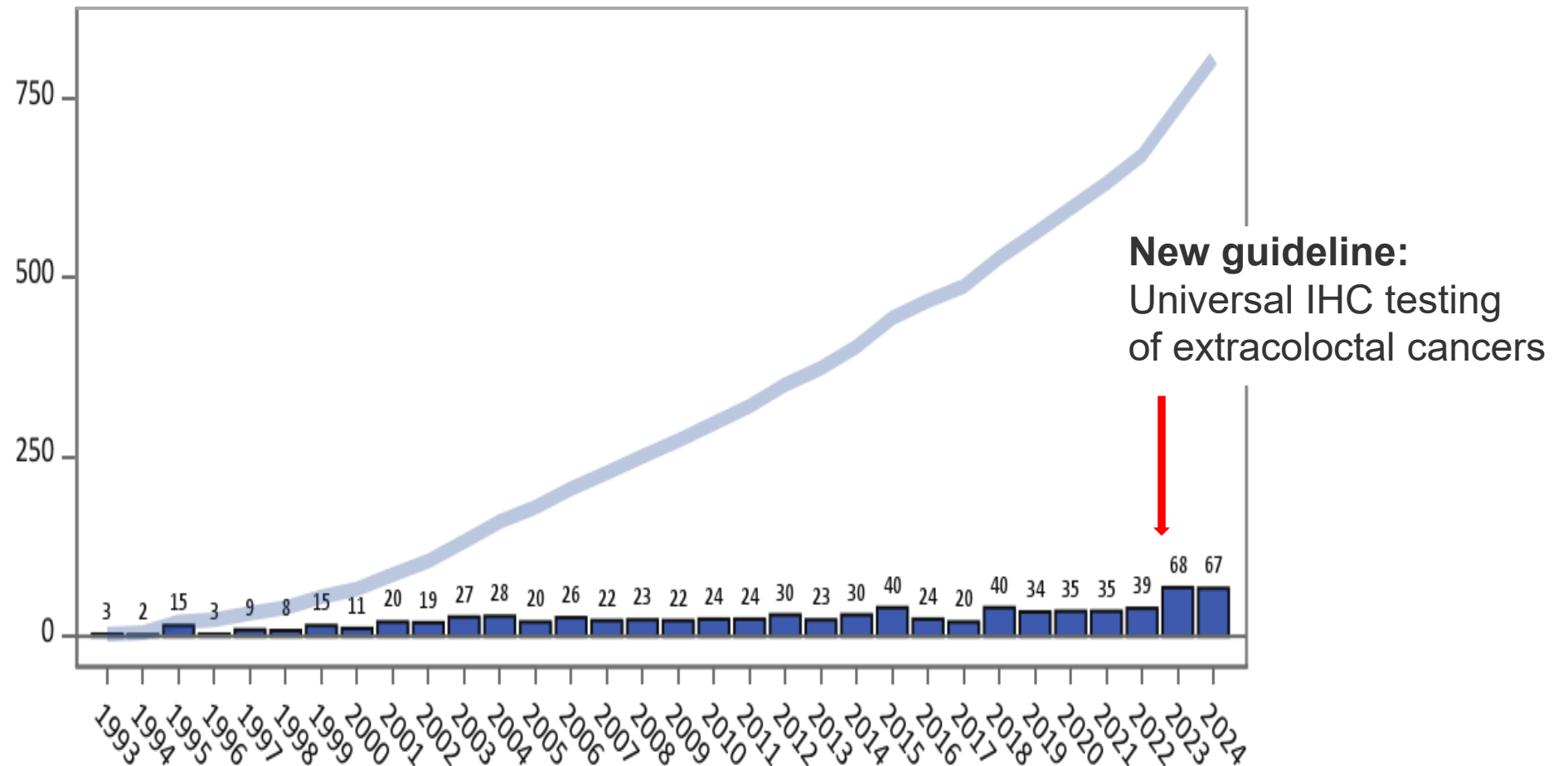


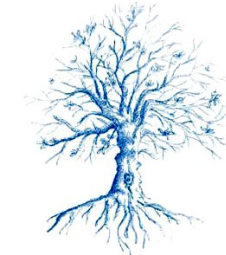
Family Classifications

- 103 old families re-evaluated in 2024
- Families with other genetic predispositions is increasing
- As are families with Lynch syndrome

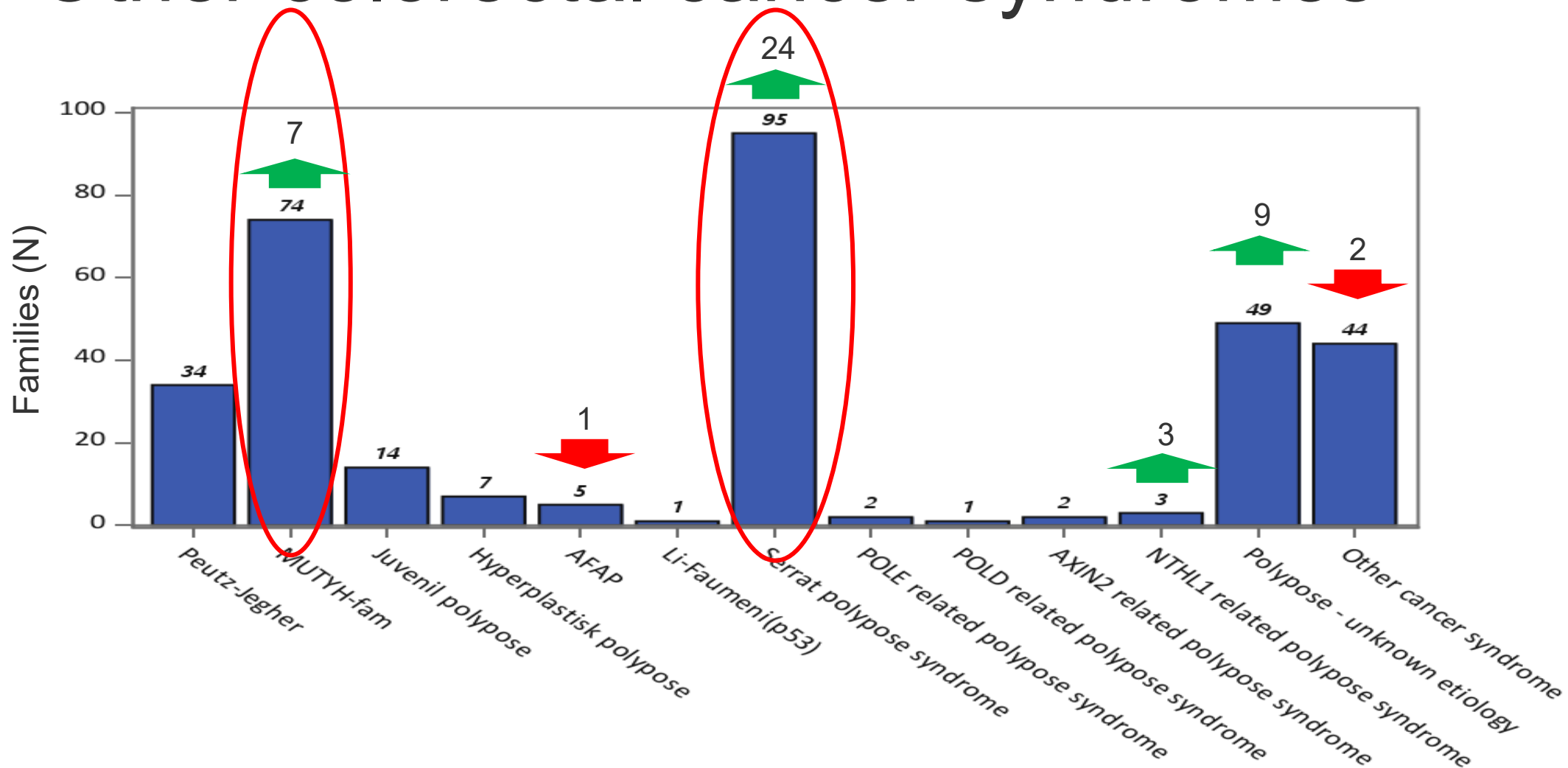


Increasing number of Lynch syndrome families





Other colorectal cancer syndromes

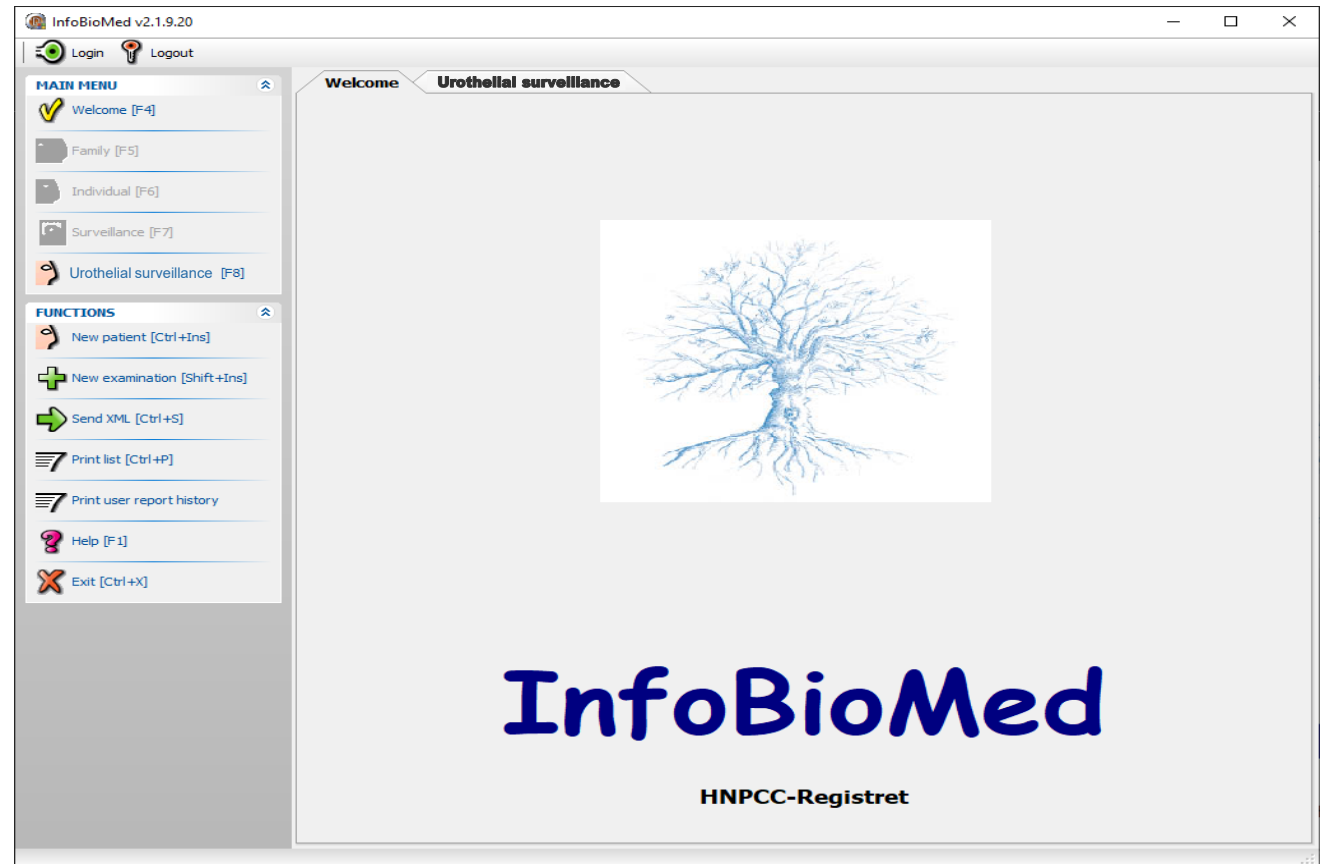


New feature in the register



New feature in the register

- Reporting outcome of urothelial surveillance
- Directly imported into the HNPCC Register
- Data quality control
- Research purposes
 - Evaluating the efficacy of the current screening tools
 - Evaluating compliance



Reports

 Welcome [F4] Family [F5] Individual [F6] Surveillance [F7] Endometrie surveillance [F8] Urological surveillance [F9]

Functions

 New patient [Ctrl+Ins] New examination [Shift+Ins] Send XML [Ctrl+S] Print list [Ctrl+P] Print user report history

General

 Help [F1] Login Logout Exit

Welcome

Urological surveillance

Patient information

Civil no 040860-0001

First name F.

Last name L.

Performing data

Indication Screening

Symptom None

Remarks

None
Haematuria, macroscopic
Pain
Lower urinary tract symptoms
Pyelonephritis
Other (describe)
Unknown

☐ Start new surveillance round

Clinical results

Date		Examination	Remarks
08-09-2025	☐	Urine dipstix	
08-09-2025	☐	Ultrasound	Tumor in pelvis
28-08-2025	☐	CT scan	Tumor in pelvis
28-08-2025	☐	MR scan	Tumor in pelvis
28-08-2025	☐	Flexcystoscopy	Normal
22-08-2025	☐	Nefroureteroscopy	Others Flonk

Pathological results

Date		Location	Examination	Result	Remarks
08-09-2025	☐	Urine cytology	Urine cytology	Paris IV Suspicious for Carcinoma	
	☐	Urine MSI			
28-08-2025	☐	Urine DNA/RNA	PCR	Abnormal	
08-09-2025	☐	Renal pelvis	Other	Cancer	Ablation
08-09-2025	☐	Ureter	Resection	CIS	
	☐	Bladder			
	☐	Urethra			
08-09-2025	☐	Metastasis	Biopsy	Cancer	
	☐	Other (describe)			

How to do rese

- Apply the **Scienti**

Lone Sunde
Thomas Bjørsum-Meyer
Lars Henrik Jensen
Karin Wadt
Zohreh Ketabi
Louise Klarskov
Stig Egil Bojesen
Christina Therkildsen

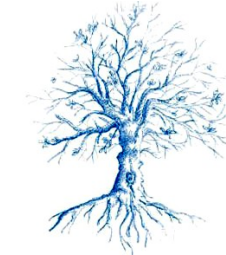
- By mailing the **ap**
- **HNPCC-Forskning.hvidovre-hospital@regionh.dk**

Opdateret 30.7.2018, vers. 2.3.

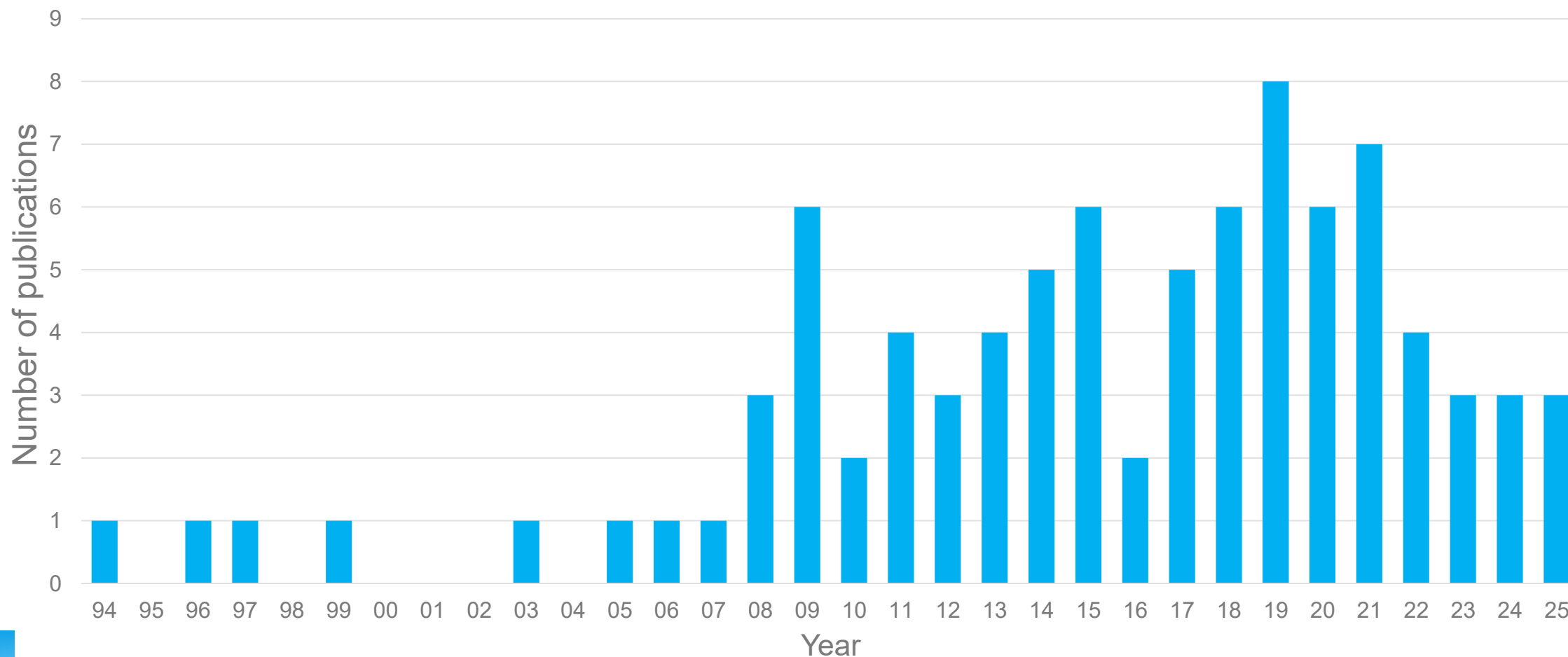
Ansøgningsskema vedr. forskningsdata fra HNPCC-registret	
Ansøgningen udfyldes og sendes elektronisk til HNPCC-registret bilagt kortfattet protokol.	
Projektets titel skal indgå i filnavnet.	
E-mail: hvb-hnpcc-forskning@regionh.dk	
Ansøgningsnummer: (udføres af HNPCC-registret) Klik her for at angive tekst.	
Projekttitel: Klik her for at angive tekst.	
Ansøger:	
Navn:	Klik her for at angive tekst.
Stilling:	Klik her for at angive tekst.
Ansættelsessted:	Klik her for at angive tekst. Navn, adresse, postnummer og by
Telefon:	Klik her for at angive tekst.
E-mail:	Klik her for at angive tekst.
Kontaktperson, hvis denne ikke er ansøger: (navn, stilling, ansættelsessted, tlf., e-mail) Klik her for at angive tekst.	
Projektdeltagere (navn, afd./institution) - alle skal medtages: Klik her for at angive tekst.	
Afdeling/institution som projektet primært udgår fra: Klik her for at angive tekst.	
Start- og slutdato for projektet:	
Startdato:	Klik her for at angive tekst.
Slutdato:	Klik her for at angive tekst.

Opdateret 30.7.2018, vers. 2.3.

Direkte kontakt til registrerede individer:	
Planlægges direkte kontakt til registrerede individer i HNPCC-registret? Ja: ☐ Nej: ☐ Hvis ja, beskriv her eller henvis til protokol: Klik her for at angive tekst.	
Oplysninger vedrørende ønskede data:	
1. Tidsperiode for dataudtræk:	Klik her for at angive tekst.
2. Studiepopulation:	Klik her for at angive tekst.
3. Evt. yderligere specificering af population	Klik her for at angive tekst.
4. Variabler der ønskes fra HNPCC-registret ¹ (kan også beskrives i protokol)	Klik her for at angive tekst.
5. Ønsket dataformat: CSV (Excel-kompatibelt), XML, SAS, andet)	Klik her for at angive tekst.
Andre oplysninger: Klik her for at angive tekst.	
¹Kun overordnede kategorier/variabelnavne for udtræk skal angives, da præcisering sker efter godkendelse af ansøgning i samarbejde med registret.	
Vil data blive behandlet af andre end de anførte projektdeltagere i indeværende ansøgning? Ja: ☐ Nej: ☐	
Hvis ja angiv navn og tilhørende organisation/institution:	



Publications using data from The Danish HNPCC Register



hnpcc-forskning.hvidovre-hospital@regionh.dk

