

NEWSLETTER NOVEMBER 2019

Dear all

We would like to thank you for your support and your continuing trust in the CASCADE study. One year has passed and we are now able to send you the second CASCADE Newsletter, in which we inform you about the current events of the study - a follow-up study awaits you!

If you have any questions, please do not hesitate to contact us at any time.

Your CASCADE study team swisscascade-nursing@unibas.ch

We thank the participating doctors and test centres for their support:













PROJECT STATUS

Survey:

Currently, study participants are being recruited from 5 different Swiss cantons: Basel, Berne, Ticino, Jura and Geneva.



To date, **290** participants, nearly 80% of whom are women, have taken part in the study.

About 40% of the participants

were willing to invite at least one family member to participate in the study. To date, many relatives have participated in the study. However, 5 to 6 times more at-risk relatives were identified in the questionnaires than those who were eventually invited to the study. Please invite your family and friends!

Interviews and focus groups:

So far, almost 20 people have shared their experiences with us, either in individual interviews or in group discussions.

How did you reach the decision to communicate/ not communicate with certain members of your family? Can you describe how your doctor approached communication within the family?

Tell us about your experiences and participate in an interview or group discussion!

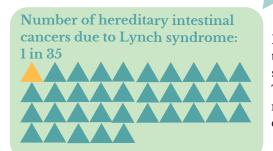


THANK YOU FOR YOUR SUPPORT!

Lynch syndrome at the center of attention:

Number of people with Lynch Syndrome: 1 in 370 80% Intestine

60% Endometrium 15% Ovary



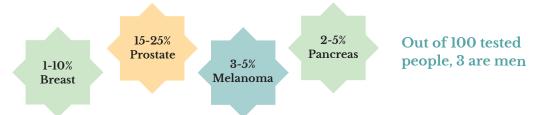
Because the clinical symptoms of different types of cancer are very different, Lynch syndrome is often left undiagnosed. Therefore, "Cascade testing" in at-risk relatives is very important to diagnose all cases, especially when cancer occurs.

If you have been diagnosed with Lynch Syndrome and are participating in the CASCADE study, please help us recruit as many of your relatives as possible.

If you need advice on how to invite your relatives to the study, please contact us by e-mail at swisscascade-nursing@unibas.ch or by phone at +41 (0) 61 207 59 85.

Men at the center of attention:

Genetic mutations involved in hereditary breast and ovarian cancers affect not only women but also men. Men with a alteration in the BRCA1 and BRCA2 genes have a higher risk of developing the following cancers:



Men who carry a BRCAl or BRCAl gene mutation can also pass it on to their children. However, men are often not tested for this genetic alteration.

Help us by inviting as many men as possible to the CASCADE study. If you are a man and are considering participating in the study but have questions first, please contact us by e-mail at swisscascade-nursing@unibas.ch or by phone at +41 (0) 61 207 59 85.

CASCADE TEAM

We welcome our new members to the CASCADE team:



Muriel Fluri is a nursing expert at the Inselspital in Berne and organises the CASCADE study in the canton of Berne.



Marion Rudaz is the new project manager and she is responsible for coordinating the study throughout Switzerland.

RESULTS

Poster presentation at the ESMO Congress, an international congress in Barcelona, Spain (27. Sept. - 1. Oct. 2019) on communication about hereditary cancer within families.

CN115: Communication of genetic information to family members in hereditary cancers and healthcare providers' role

C Pedrazzani, M Caiata-Zufferey, A Kaiser-Grolimund, N Bürki, O Pagani, M C Katapodi Annals of Oncology, Volume 30, Issue Supplement_5, October 2019, mdz277.008, https://doi.org/10.1093/annonc/mdz277.008

Funding of a new project based on the CASCADE study by the Swiss National Science Foundation and the National Research Foundation in Korea: "The DIALOGUE Study: Using Digital Health to Improve Care for Families with Predisposition to Hereditary Cancer" (in short: DIALOGUE Study), for 4 years.

Bilateral collaboration between Switzerland and South Korea with the implementation of the CASCADE study in Korea: K-CASCADE. More information soon available on: http://www.snf.ch

We would like to thank the following donors for their support of the CASCADE study:



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