



Minisode 1 Transcript: Getting Involved in the International Scalp Cooling Registry

SPEAKERS

Dr Corina van den Hurk, Dr Maryam Lustberg, Richard Paxman

Richard Paxman 00:00

Hi, my name is Rich Paxman, and welcome to the Changing the Face of Cancer podcast. In this bonus episode, Corina van den Hurk of the Netherlands Comprehensive Cancer Organisation, discusses the expansion of the Dutch Scalp Cooling Registry to include international data. Following the success of the database of over 7000 patients scalp cooling results, which has provided a vital insight into scalp cooling efficacy. Maryam Lustberg, Chief of Breast at Yale cancer centre also expresses her support for the registry, as it continues to drive the movement towards precision symptom management within cancer care. As well as providing an insight on how Corina and her team are increasing their analysis of the registry to measure further variables. We also discuss the gaps in scalp cooling research, and what the future holds for collecting this all important data. Listen to find out how you can be part of the international Scalp Cooling Registry, and help shape this database to better educate and inform both clinicians and patients in the future. Thank you for listening. So the Dutch Scalp Cooling Registry is an absolutely fantastic project. It would be wonderful if you could talk a little bit about the registry, the data you've collected so far, some of the key sort of results areas, but perhaps as well more about the future and what your plans are for it. Because I think that could be really exciting to learn and for the audience to understand how they might be able to get involved in the future.

Corina van den Hurk 01:36

Yes, yes, of course, well we had our 7000 patients, indeed, that were also collected from the real world. So each patient that started scalp cooling could join the registry. So that also makes that it is about people who are 20 years old, or 80 years old, and men and women from all kinds of ethnicities, indeed. So we're now also taking a look more in depth, we first took a look, of course at the efficacy for several chemotherapies and dosages, but now also more taking a look at for example, differences between wetting and not wetting the hair, or post infusion cooling times, or infusion times of the chemo. And also what does that do with the result of scalp cooling, and doing multivariate analysis to see what factors are important to make it work even better. So that's what we are working on now together with some students. And for the forthcoming year, we will also align with Huddersfield University also to use the data to take a more look in depth in in all kinds of topics that we haven't addressed yet, because we also, for example, collected data on smoking and alcohol use, etc. And all those kinds of variables that might be determinants of the effects. And we haven't used that data yet. So that's really a pity.



And we really want to use it, we set up an digital infrastructure in Dutch and an English, so each English speaking country can join already. And we have our first meeting in September. We had a small subgroup of oncodermatology, a study group of MASCC, and then we will talk about how we can divide our tasks among those people who are enthusiastic to join. And also make it work because I first thought that I could start it by myself and do everything, but it is way too much, so we have to do it together. So that's where we will start with the international part. And that means that within one country, there's one contact researcher or nurse or someone who is taking the lead in that country, we can make accounts for the several hospitals and the healthcare professionals. And then if there is a patient who want to use scalp cooling and wants to join the registry, then the person in the hospital makes an account for the patient. And then everything can be done by the patient. And then you see within your country, the results of scalp cooling on the back end of the system. So you can see how many patients there are, you can also download the results from your own hospital, you can compare your hospital with the other hospitals in the country. And if there are not that many hospitals, and we will put it together for a few countries. So you have immediately also some feedback to take a look at best practices, where you can learn from our results if they are less good than the general results of the country, what do we do different from them? So it's also a little bit benchmark possibility. And yeah, it is open for scalp-cooled patients and not non-scalp-cooled patients. Because then we also have more insight in how much hair loss there is in patients who don't use scalp cooling because for some chemotherapy, it is obvious what the incidence of severe hair loss is, but for other it is more doubtful. And then you just get an estimation from nurses and it is better to have some data to really see what the added value of scalp cooling is.

Richard Paxman 04:48

A couple of things there. I think that benchmarking I think from country to country or site to site is really helpful and perhaps even creates a little bit of competition to make sure we do the best for our patients. to provide the best education, the best support, which ultimately does lead to the better results. Another area for me is, it's not just about collecting data, is it and presenting data, but it's actually about how do we improve what we're doing? How do we get better results? What is that best practice, and that's, I think that's so important. You know, we often talk about this, its 50/50 chance in reality, but we have to find ways and work together collaboratively to improve our results. And ultimately, we don't want anyone to lose their hair longer term, and perhaps we'll get to that stage one day, and that will be fantastic. But in the meantime, we need to look at interventions as well as scalp cooling, perhaps to improve that overall efficacy. And that's, that's what I'm, I'm really excited about for the future.



Corina van den Hurk 05:46

And then it's first there is the registry, with the data from the daily clinical practice. But at the other end to further improve the results, I think that we really need some additional research, because if you look at PubMed, there are still the reviews of all the papers that have been published. And it is about efficacy of scalp cooling in one or some hospitals with one or some chemotherapy types. So that's the same thing that's done over and over again. But if we take a look, for example, on at post infusion cooling times, what does that do with the result and can we shorten it to also that the patient can go home more earlier, but we're here in the Netherlands now also taking a look at the temperatures that we can measure in the first 10 minutes. And then we can predict how low the temperature for that particular patient would be. So we can adjust the temperature of the machine. And if my head would be too warm after 10 minutes, the prediction is that it stays too warm, then we can make it work that my scalp skin temperature becomes somewhat cooler to have more chances for success. Last week, also in cancers at work, there was a paper and that was about pharmacokinetics during scalp cooling. So that's also a particular topic showing different things, so not only about efficacy, but about safety and about improving the results and doing different things. So I think we need both a registry to see how we are doing and to search for best practices. And on the other hand, trying to do new things to make it even better.

Maryam Lustberg 07:17

Such incredible work you're doing Corina, I like to call this precision supportive care, or precision symptom management - really trying to personalise. Right now it's we're saying one cap fits all one size fits all for some of our interventions, but to try to really tailor and teach patients to optimise success. I really love the ideas you're sharing.

Richard Paxman 07:41

Excited about it as I think we both know we have the temperature study ongoing at Memorial Sloan Kettering with Mario Lacouture and Shari Goldfarb at the moment. So hopefully that will provide some insight, albeit it's not powered to give us a definite result, longer and shorter post cooling times continue to be a debate. And I think will be and I think that whole idea of a longer post infusion cooling times scares us all in terms of infusion chair time, especially in places like America, where time is really is money, but we've got to find the right information, haven't we hopefully, and then the Research Centre at Huddersfield, looking at something topical. So we've developed a compound which in vitro showing really promising results that improve cell viability, so used in conjunction with scalp cooling. So the next steps for that is to look how we can deliver that to the hair follicle. So that'll be an exciting project for us and then ultimately, actually checking if it works in real life. So whether that be a clinical trial or something of a similar nature, but really pushing that needle and improving the



efficacy of scalp cooling overall. But if anyone is interested in the registry that is listening today, please do let us know and I'll hook you up with Corina and hopefully you can talk and get involved at some point.