Reykjavík den 23 maj 2016

NCU:s styrelsemöte i Reykjavik den 30 maj 2016.

Förslag till dagordning

Mötesordförande: Ragnheiður Haraldsdóttir, Island.

Mötesplats: NAUTHÓLL, Nauthólsvegi 106, 101 Reykjavík.
Mötestid: Kl. 09:30 – 15:30.

Inledning

1. Mötets öppnande.
2. Godkännande av dagordning.
3. Godkännande av referat.
4. Översikt över strategiska projekt.

Beslutsfrågor

5. Godkännande av nya stadgar för NCU.
6. Preventiva åtgärder för att minska rökningen i Norden.
- World No Tobacco Day for 2016.
7. European Task Force for Equal Access to Cancer Medicines-Declaration of Intent.

Kl.: 11.00

Information och diskussion

8. Jämförelse av Nationella Cancerhandlingsplaner i Norden.

Kl.: 13:00

9. NCU och Cancer Screening i Norden.
10. Status over "avoidable cancer" projektet (NORDCAN projektpakken).
11. Immigranter och cancer.
12. Cancer research and genetics in Iceland.
13. Rapporter från länderna.
14. Övriga frågor.
- ANCR & NCU Symposium 2016.

Avslutande frågor

15. Kommande möten.
16. Mötets avslutande (Kl.: 15:30).
17. Besök till Presidentens residens att Bessastaðir (Kl.: 16:00).

Reykjavík den 23 maj 2016

NCU:s styrelsemöte i Reykjavik den 30 maj 2016.

Dagordningskommentarer

Mötesplats: NAUTHÓLL, Nauthólsvegi 106, 101 Reykjavík.
Mötestid: Kl. 09:30 – 15:30.

Inledning

1. **Mötets öppnande.**

- NCU:s ordförande Ragnheiður Haraldsdóttir förklarar mötet öppnat.

2. **Godkännande av dagordning.**

- Ordföranden föreslår att dagordningen kan godkännas.

3. **Godkännande av referat.**

- Ordföranden föreslår att referat från senaste möte kan godkännas.

4. **Översikt över strategiska projekt.**

- Ordföranden redogör för läget gällande de strategiska projekten.

Beslutsfrågor

5. **Godkännande av nya stadgar för NCU.**

Bilagor:

5.1 Cover letter.
5.2 Draft proposal for change of the Statutes of the Nordic Cancer Union.
5.3 Stadgar för Nordiska Cancer Unionen.

Arbetsgruppen för administrativa funktioner träffades i Köpenhamn den 17 mars och enades om föreliggande förslag till nya stadgar för NCU.

Förslag:

Styrelsen godkänner förslag till nya stadgar för Nordiska Cancer Unionen.

6. Preventiva åtgärder för att minska rökningen i Norden.

- World No Tobacco Day for 2016 on the 31st of May.

Bilagor:

6.1 Cover letter. Call for plain packaging in the Nordic Countries.

Ole Alexander Opdalshei informerar om nya idéer och planer för att ytterligare reducera rökningen i Norden.

Förslag:

Styrelsen ställer sig bakom deklarationen och dsikuterar hur mar skall arbeta vidare med saken.

7. European Task Force for Equal Access to Cancer Medicines-Declaration of Intent.

Bilaga:

7.1 Cover letter.
7.2 European Task Force for Equal Access to Cancer Medicines- Declaration of Intent.

Leif Vestergaard Pedersen och Sakari Karjalainen redogör för innehållet i ländernas deklaration beträffande att säkra invånarna jämn tillgång på cancermediciner.

Förslag:

Styrelsen beslutar att ställa sig bakom deklarationen om tillgång på cancermediciner.

Kl.: 11.00

Information och diskussion

8. Jämförelse av Nationella Cancerhandlingsplaner i Norden.

Bilagor:

8.1 Cover letter. Vägledande frågor för presentation och följande diskussion.

Ingimar Einarsson ger en kortfattad överblick över hur regionala och nationella hälsoprogram har utvecklats de senaste årtionden.

Därefter redogör respektive land för sin Nationella Cancer Program, 10-15 minuter per land.

Förslag:

Styrelsen utväxlar information och synpunkter.

Lunch kl. 12:00 – 13:00

9. NCU och Cancer Screening i Norden.

Bilagor:

9.1 Cover letter.
9.2 NCU and screening for cancer in the Nordic countries.

Ragnheiður inleder diskussion om eventuellt deltagande av NCU i nordiskt samarbete på området.

Förslag:

Styrelsen utväxlar information och synpunkter.

10. Status over "avoidable cancer" projektet (NORDCAN projektpakken).

Bilaga:

10.1 Status over "avoidable cancer" projektet. Cover letter.

Den senaste delen av NORDCAN projektpaketen är genomgåendet av beräkningar av cancerfall som man borde ha kunnat undgå med målinriktade förebyggelseinsatser. Hans Storm kommer att redogöra för resultaterna av de första analyserna.

Förslag:

Styrelsen utväxlar information och synpunkter.

11. Immigranter och cancer.

Bilaga:

11.1 Immigranter och cancer. Cover letter.

Laufey Tryggvadóttir, direktör för Cancerregistreret i Island, redogör för den information som föreligger om cancer bland immigranter i Norden.

Förslag:

Styrelsen utväxlar synpunkter.

12. Cancer research and genetics in Iceland.

Bilaga:

12.1. Cover letter.

Dr. Þórunn Rafnar, scientist at deCODE genetics, informerar om resultater av det forskningsarbetet försiggår inom cancerområdet på deCODE genetics.
Samt företagets idéer om forskning i framtiden.

Förslag:

Styrelsen utväxlar synpunkter.

13. Rapporter från länderna.

Delegationerna redogör för situationen i respektive land.

14. Övriga frågor.

- ANCR & NCU Symposium 2016.

Avslutande frågor

15. Kommande möten.

Nästa möte äger rum den 1 september i Finland och därefter räknar man med möte den 25 november.

16. Mötet avslutar klockan 15:30.

17. Besök till Bessastadir startar kl. 16:00.

DELTAGARLISTA

Danmark
Dorthe Gylling Crüger
Leif Vestergaard Pedersen
Hans Henrik Strom
Elizabeth Hjorth

Finland
Sakari Karjalainen
Ritta Pyhälä

Island
Kristján Oddsson
Ragnheiður Haraldsdóttir
Ingimar Einarsson
Lauvey Tryggvadóttir (pkt. 11)
Ófeigur Tryggvi Þorgeirsson (pkt. 8)
Þórunn Rafnar (pkt. 12)

Norge
Ole Alexander Opdalshei
Kirsten Haugland

Sverige
Sanna Wärn

Färöarna
Durita Tausen

Bilagor

Pkt. 2	Förslag till dagordning.
Pkt. 3	Referat från NCU:s möte i Oslo den 19 februari.
Pkt. 4	Strategic projects verview.
Pkt. 5	5.1 Cover letter. 5.2 Proposal for change of the Statutes of the Nordic Cancer Union. 5.3 Statutes of the Nordic Cancer Union.
Pkt. 6	31.5.2016 – World No Tobacco Day (draft 04.05.16).
Pkt. 7.	7.1 Cover letter. 7.2 DECLARATION OF INTENT – European Task force for equal access to cancer medicines.
Pkt. 8	8.1 Cover letter.
Pkt. 9	9.1 Cover letter. 9.2 NCU and screening for cancer in the Nordic Countries.
Pkt. 10	10.1 Status over "avoidable cancer" projektet (NORDCAN projektpakken).
Pkt. 11.	11.1 Cover letter. Cancer and immigration in the Nordic Countries.
Pkt. 12.	12.1 Cover letter. Cancer research and genetics in Iceland.
Pkt. 14	14.1 ANCR & NCU Symposium 2016.

NCU rev ref 090316

Reykjavík den 9 mars 2016

Referat

Från möte i Nordiska Cancer Unionens styrelse i Oslo den 19 februari 2016.

Mötesplats: Kreftforeningen, Kongens gate 6, Oslo.
Mötestid: Kl. 10:30 – 16:00.

Inledning

1. **Mötets öppnande.**

   Ordföranden öppnade mötet.

2. **Godkännande av referat.**

   Styrelsen godkände utkast till referatet från telefonmötet den 2 december 2015.

3. **Godkännande av dagordning.**

   Styrelsen godkände förslaget till dagordning av den 17 februari 2016.

   Deltagarna diskuterade också den potentiella förekomsten av motstridiga intressen gällande enskilda punkter på dagordningen. I sådana fall får var och en bedöma om man skall avstå ifrån att delta i behandlingen av dessa frågor eller endast själva besluten.

Beslutsfrågor

4. **Räkenskaper för 2015.**

   Revisor Rögnvaldur Dofri Pétursson genomgick och förklarade räkenskaperna för året 2015.

   Beslut:
   Styrelse fastställde räkenskaperna för 2015.

5. **NCU: s budget för 2016.**

   Revisor Rögnvaldur Dofri Pétursson redogjorde för förslaget till budget för året 2016.

Från norsk och dansk sida framfördes önskemål om att översikten också borde innehålla information om budgetutvecklingen de senaste 2-3 åren.

Beslut:
Styrelsen fastställde budgeten för året 2016.

1. **Revidering av strategi och riktlinjer för strategiska fonder.**

Ragnheiður Haraldsdóttir redogjorde för tidigare diskussioner inom styrelsen och förslaget till en ny strategi och riktlinjer för de strategiska fonderna. Två versioner av strategier och riktlinjer presenterades, version A och version B. I styrelsen rådde bred enighet om att stödja version A. Den innebär att strategiska projekten kommer i flesta fall att initieras av NCU: styrelse, men dessa kan också ha sitt ursprung annanstans.

Beslut:
Styrelsen godkände version A.

2. **Stöd till strategiska projekt.**

Styrelsen uttryckte sin glädje med översikten över de strategiska projekten och menade att den kunde vara till stor nytta för det framtida arbetet.

Sakari Karjalainen redogjorde för CONCORD-projektet och sina samtal med Michel P. Coleman. Styrelsen är inte beredd att stödja detta projekt, men pekar på att ökat samarbete mellan CONCORD och NORDCAN ändå kan bli fruktbart.

Beslut:
Ragnheiður Haraldsdóttir skriver utkast till ett brev till Coleman och det skickas ut till styrelsemedlemmarna för kommentarer innan det sänds iväg.

Ragnheiður Haraldsdóttir informerade om en ansökan från DAMVAD-ANALYTICS som redan översänts till vetenskapskommittén. Styrelsen är enig med vetenskapskommittén om att respektive ansökan inte kan godkännas i sin nuvarande form.

Beslut:
Ragnheiður Haraldsdóttir skriver utkast till svarsbrev till Rasmus Lund Jensen och det skickas ut till styrelsemedlemmarna för kommentarer innan det sänds iväg.

Hans Henrik Storm redogjorde för NORDCAN:s verksamhet de senaste åren och framtidsplaner. Nu söker man finansiellt bidrag för en tre års period. Hans Henrik sammanställer en kort lägesrapport som tas upp vid styrelsens nästa möte i Island den 30 maj. Hans Henrik deltog inte i beslutet gällande ekonomiskt stöd till NORDCAN.

Beslut:
Styrelsen godkände NORDCAN:s ansökan som innebär årligt stöd om 35 500 Euro i tre år (2016, 2017 och 2018).

Information och diskussion

8. **Norska Kreftforeningens verksamhet.**

Från norska sida redogjorde man för vad Kreftföreningen arbetar med nu för tiden och visade styrelsen de nye lokalerna i Kongens gate 6.

Norge orienterade om två områden. För det första Kreftforeningens aktionsplan för preventiva åtgärder och tidig detektion av cervical cancer, och för det andra arbetet med ny strategi beträffande finansiering av forskning. Ingrid Stenstadvold Ross och Kirsten Haugland informerade på mötet om pågående aktiviteter gällande preventivt arbete och åtgärder för att få fram budskapet via socialamedia till allmänheten. Norska Kreftforeningen kommer att skicka Slides till NCU sekretariatet. For det andre jobber Kreftforeningen nå med å endre rutinene for forskningstildeling, bla inkludere flere internasjonale fagfeller (for å redusere habilitetsutfordringer), forenkle administrative rutiner knyttet til evaluering, innføre ett nivå, og inkludere brukerne både i strategi og evalueringsprosess.

Beslut:
Styrelsen tog informationen till kännedom.

9. **Revidering av NCU:s stadgar.**

Ragnheiður Haraldsdóttir och Elizabet Hjort redogjorde för arbetet i samband med revideringen av NCU:s stadgar. Förhoppningsvis bör detta arbete kunna avslutas vid mötet i Island i slutet av maj.

Beslut:
Styrelsen tog informationen till kännedom.

10. **NCU:s sekretariatsfunktioner.**

Susanna Wärn informerade om arbetet inom arbetsgruppen beträffande NCU:s administrativa funktioner/sekretariat. Nästa möte i arbetsgruppen blir den 17 mars i Köpenhamn. Under mötet kommer man att diskutera särskilt revideringen av stadgarna, inklusive sekretariatsfunktionerna.

Beslut:
Styrelsen beslöt att Ragnheiður och Elizbeth förbereder mötet i Köpenhamn.

11. **Nordic trial alliance stakeholder meeting.**

Ole Alexander Opdalshei redogjorde för vad som framkommit vid NTA Stakeholders Meeting som hölls i Oslo den 26 januari 2016. Ole Alexander kommer att distribuera presentationer från mötet till styrelsens medlemmar. Hans Henrik informerade om den nya Europeiska regleringen av kliniska försök samt patienternas rätt att söka hälso- och

sjukvård i andra länder. Man kom överens om att alla skulle skicka Ole Alexander en kort redogörelse för hur detta fungerar i respektive land.

Beslut:
Styrelsen tog informationen till kännedom.

12. **ANCR Symposium 2016.**

Sakari Karjalainen redogjorde för förberedelserna inför det ANCR:s Symposium år 2016 som kommer att äga rum vid månadsskiftet augusti/september i Finland. Där blir samtidigt ett gemensamt möte mellan styrelserna för NCU och ANCR. Sakari kommer att sammanställa en kort Pro Memoria som ett inlägg i förberedelserna inför evenemanget.

Beslut:
Styrelsen tog informationen till kännedom.

13. **Multinationellt samarbete.**

Sakari Karjalainen redogjorde för det pågående samarbetet inom ECL (The Association of the European Cancer Leagues). ECL har fått finansiellt bidrag från EU (som kommer att underlätta deras arbete den närmaste tiden och) som ska användas att göra European Code Against Cancer känd. ECL arrangerar (deltar i) The European Week Against Cancer som äger rum i slutet av majmånad varje år. Det framgick också att ECL arrangerar sin generalförsamling på söndag den 30 oktober i Paris just före The World Cancer Congress som äger rum 31.10.-3.11. 2015. Det framgick också att Elizabeth Hjorth har så sent som i veckan förre NCU:s möte deltagit i ett förberedande telefonmöte.

Information om aktiviteter in om UICC (The Union for International Cancer Control) blev uppskjuten eftersom Anne Lise Ryel inte hade möjlighet att delta i mötet. Hon kommer däremot till mötet i Island i maj och kan då avge sin rapport om läget.

Beslut:
Styrelsen tog informationen till kännedom.

14. **UICC – who decides policy.**

Hans Henrik informerade om den situation som uppstått inom UICC mellan UICC CEO Gary Adams och Professor Michel Coleman LSHT. Styrelsens bedömning var att detta inte var någon NCU-fråga. Endast en sak mellan UICC och Michel Coleman. I fortsättningen av mötet har det också framkommit att saken redan är löst.

Beslut:
Styrelsen tog informationen till kännedom.

15. **Rapporter från länderna.**

Från norsk sida redogjorde man, i tillägg till det som tidigare framkommit, för åtgärdsprogrammet Samlade Krefter mot kreft, Helsekonferens som äger rum i mars, Goldfish prisen och programmet Gi for Livet!

På Färöarna har man startat med nåbokaffe för att samla in pengar som stöd för cancerföreningarnas verksamet, samtidigt som man försöker engagera folk att komma ut att gå och i tillägg har Thorshavns Marathon har blivit en inkomstkälla för cancerrörelsen. Folk behöver inte löpa helt Marathon. Det går också bra att löpa kortare sträkor.

I Sverige har folkhälsoministern Gabriel Wikström engagerad sig i att minska rökningen så den blir under 5% år 2025. Året 2014 blev 60 tusen människor diagnosterad med cancer i Sverige och man räknar med att om 20 år blir den årliga siffran sannolikt uppe i 100 tusen.

I Danmark har man ingått av tal med TV för att lyfta fram frågor gällande prevention och behandling av cancer. Aktiviteter arrangeras genom sociala media. Man försöker rikta sitt arbete mot att hjälpa unga flickor. Prioriteringskommission tar ställning till i vilken utsträckning man bör ge dödande patienter dyra mediciner. Cancerplan är under utarbetande samt etiska regler och vägledande riktlinjer för användning inom hälso- och sjukvården.

I Finland lägger Cancerföreningen i Finland och Cancerstiftelsen vikt vid samarbete mellan olika parter nationellt och är samtidigt mycket aktiv i internationellt samarbete på cancerområdet. Året 2016 fyller Cancerföreningen i Finland 80 år. Cancerföreningen och Cancerstiftelsen har en ny gemensam strategi. Det ska förverkligas via så kallade spetsprojekt och en utvecklingsplan.

I Island har Cancerförbundets ekonomi förstärkts de senaste åren. Nyligen har man etablerat en ny cancerfond för att väcka liv i forskningen inom cancerområdet. Vidare har Cancerförbundet ingått avtal med hälsoministern Kristján Þór Júlíusson om att åta sig att systematik införa koloskopi av män i åldern 60-69 år.

16. **Övriga frågor.**

Jákup N. Olesen avgår som ledamot i NCU efter nästan 30 år i styrelsen. Ordföranden tackade honom för en betydelseful insats genom åren och överlämnade en gåva som uttryck för styrelsens tacksamhet. Tidigare har det också framkommit att Stefan Bergh har slutat som ledamot i styrelsen och bad ordföranden Sanna Wärn om att ta med sig en gåva till honom från styrelsen.

Avslutande frågor

17. **Kommande möten.**

    Följande två styrelsemöten kommer att äga rum i Island den 30 maj respektive i Finland den 31 augusti och den 1 september.

18. **Mötets avslutande.**

    Ordföranden avslutade mötet.

Ragnheiður Haraldsdóttir
NCU Ordförande

Ingimar Einarsson
NCU Coordinator

DELTAGARLISTA

Danmark
Hans Henrik Strom
Elizabeth Hjorth

Finland
Sakari Karjalainen

Island
Ragnheiður Haraldsdóttir
Ingimar Einarsson
Rögnvaldur Dorfi Pétursson

Norge
Ole Alexander Opdalshei
Kirsten Haugland
Kristin Wold Guldvog

Sverige
Sanna Wärn

Färöarna
Jákup N. Olesen
Durita Tausen

NCU - 30/5 2016
a.i. 4

NORDIC CANCER UNION

Strategic projects overview

Project overview - Oslo 19 February 2016, All amounts in EURO

Confirmed financial support	Notes	Total support	Planed in 2015	Planed in 2016	Planed in 2017	Planed in 2018	Planed in 2019
Secretariat for Nordic NECT	1	148.000	48.000	50.000	50.000		
UICC/IARC summer school	2	49.200	16.400	16.400	16.400		
NORDCAN	3	106.500		35.500	35.500	35.500	
Total confirmed support		**303.700**	**64.400**	**101.900**	**101.900**	**35.500**	**0**

Actual payments	Total support	Actual in 2015	Actual in 2016	Actual in 2017	Actual in 2018	Actual in 2019
Secretariat for Nordic NECT	148.000	48.000				
UICC/IARC summer school	49.200	13.227				
Total actual payments	**197.200**	**61.227**	**0**	**0**	**0**	**0**

Notes:

1. Confirmed on a Board Meeting in ?????? 2015
2. Confirmed on a Board Meeting in ?????? 2015
3. Confirmed on a Board Meeting in Oslo 19 February 2016

NCU meeting 30.05.16

Agenda item 5.1. Cover letter

To the Board of the Nordic Cancer Union

The proposed changes in our statutes are the result of all of our revisions in the last months.

These revisions have been aimed at clarifying and simplifying as well as bringing the statutes closer to what is feasible and practical in our current circumstances.

As the proposed changes have been scrutinized and discussed electronically, the hope is that the NCU Board meeting in May 30th 2016, can make additional suggestions as needed and that then the changes can be adopted.

Reykjavik, May 20th 2016

Ragnheiður Haraldsdottir

NCU 30.05.16

Agenda item 5.2

Proposal for change of the

Statutes of the Nordic Cancer Union

§ 1 Preamble

The Nordic Cancer Union (NCU) is a collaborative body for co-operation on relevant strategic issues, exchange of experiences and inspiration of new initiatives for the Danish Cancer Society, the Faroe Cancer Society, the Cancer Society of Finland, the Icelandic Cancer Society, the Norwegian Cancer Society and the Swedish Cancer Society.

The overall strategies and priorities for NCU are stipulated for three-year periods by the NCU Board and should be valid during a member countries chairmanship.

§ 2 Aim and strategy

The aim of the NCU is

Provision of a forum for exchange of knowledge and discussion amongst the Nordic cancer societies.

Collaboration to improve knowledge and understanding of cancer diseases, effective prevention and health promotion, results of cancer treatment and rehabilitation; and to enhance effective application in the Nordic area.

Funding Nordic research and strategic projects of highest possible standards and of relevance to the member organizations within the field of cancer according to strategies on research and strategic projects decided by the NCU Board at any given time.

§ 3. Registered office

The Board makes decisions regarding the location of the registered office site.

§ 4. The NCU Board

The NCU is governed by a Board comprising representatives of each of the member organizations of NCU.

Each organization may appoint up to three representatives for participation in board meetings – one of these at CEO and/or chairman level. Specialists/staff members of the member organizations may participate in board meetings and/or represent the members. The Board is responsible for informing the chairmen of meetings, when a need for their presence arises.

Voting in the Board is on the basis of one organization one vote. Decisions of the Board are taken by a simple majority of the Board members present. In the event of a tied vote, the NCU chairman has a second, casting vote.

4.1 The Board makes decisions congruent with the aim and strategies of the NCU concerning

- Grants for strategic projects.
- Grants for scientific projects after recommendations from the Scientific Committee.
- Other issues, e.g. with joint statements.

4.2. The Board approves

- Every three years the chairmanship for the coming three-year period.
- Every three years the strategic plan for the coming three-year period.
- Change of statutes.
- Meeting plan for at least the coming two meetings.

4.3. The Board may decide

- To establish committees and appoint committee members.
- To hold workshops in connection with board meetings and decide main themes for such workshops e.g. regarding discussions of actual, principled cancer relevant issues, long-term strategies and evaluation of activities.

4.4 The Board has 3–4 annual meetings. Main topics of the meetings include:

- Exchanges of experiences, decisions on strategic projects when needed.
- Approval of annual budget including allocation between strategic and scientific projects.
- Report from the scientific committee and progress reports from strategic projects.
- Approval of accounts and annual report for previous year.

4.5. The minutes of the Board are adopted electronically and formally signed at the following meeting by a representative from each member organization participating in the meeting.

§ 5 Chairmanship and Secretariat

The chairmanship is held alternately by the members for a three-year period taking effect from the start of a calendar year.

The chairmanship of the NCU is responsible for the Union's secretariat function during the mandate period in relation to general matters and the scientific committee. The responsibility for the NCU secretariats function may be transferred to another member country than that of the NCU chairman by a specific agreement, which has to be accepted by the majority member countries. Similarly, the responsibility of the secretariat of advisory committees, including the scientific committee, may by a specific agreement for a period of time be transferred to another member organisation than that of the NCU chairman.

NCU contributes to the costs of the secretariats as decided by the Board.

§ 6 Scientific Committee

The Scientific Committee comprises one member with scientific competence from each member country appointed by the NCU Board after recommendations from the national cancer societies.

The tasks of the Scientific Committee are:

To assess scientific grant applications and secure that they are aligned with the NCU research strategy and of high scientific quality, and formulate recommendations regarding the applications to the NCU Board for the Boards decisions on grants.

To give consultation concerning strategic projects regarding research to the Board for its decisions on grants.

To evaluate funded research and follow-up on the application of the results in the Nordic countries.

The chairman of the Scientific Committee is invited to an annual meeting with the Board.

§ 7 Finances

The NCU's funds are deposited and managed in a separate account by the cancer society which receives the funds that are placed at the disposal of the Union.

The annual budget, cost allocation between the members and balancing of the accounts are approved by the Board. The accounts are formally revised by a certified public accountant and informally by the previous chairmanship, prior to a presentation to the Board

The NCU may receive grants and donations, from which it may pay out grants and provide support for strategic projects.

§ 8 Signatories

The chairman of NCU or two other Board members authorised by the Board may sign jointly on behalf of the NCU.

§ 9 Changes of statutes and dissolution of the Nordic Cancer Union

Any member of the NCU may propose changes to the statutes and these shall be sent to the Secretariat of the NCU and communicated by the Secretariat to all NCU members not later than two months prior to the meeting for the Board.

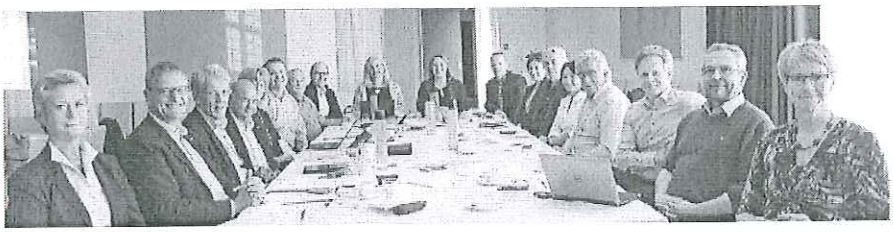
The chairman or two members of NCU may call for an extra-ordinary meeting of the Board with at least two months' notice stating the agenda.

The quorum of attendance required for changes of statutes or dissolution is at least three quarters of full members present or voting by proxy.

In the event of the dissolution of NCU, any financial assets owned by the NCU shall be distributed among its members in proportion to the apportioning index.

Statutes approved by the NCU Board ? on May 30th 2016 and adopted immediately.

NCU
agenda item 5.3



Statutes of the Nordic Cancer Union

§ 1 Preamble

The Nordic Cancer Union (NCU) is a collaborative body for co-operation on relevant strategic issues, exchange of experiences and inspiration of new initiatives for the Danish Cancer Society, the Faroe Cancer Society, the Cancer Society of Finland, the Icelandic Cancer Society, the Norwegian Cancer Society and the Swedish Cancer Society.

The overall strategies and priorities for NCU are stipulated for three-year periods by a Committee of Representatives comprising the chairmen of the member organisations.

§ 2 Aim and strategy

The aim of the NCU is

- collaboration to improve knowledge and understanding of cancer diseases, effective prevention and health promotion, results of cancer treatment and rehabilitation; and to enhance their effective application in the Nordic area.
- to fund Nordic research and strategic projects of high standards within the field of cancer

§ 3 Committee of Representatives

1. The Committee of Representatives comprises the chairmen of the member organisations.

2. The Committee of Representatives meets every third year in the autumn.

3. The chairman or two members of NCU may call for an extra-ordinary meeting for the Committee of Representatives with at least two months' notice stating the agenda.

4. The tasks of the Committee of Representatives are to

- approve the strategic plan for the coming three-year period based on the recommendation from the Secretaries-General
- approve the report and evaluation of the NCU activities in the past three-year period
- approve the chairmanship for the coming three-year period
- perform changes of statutes
- approve observer members

5. A scientific conference may be held in connection with the meeting for the Committee of Representatives. The main themes of the conference are decided by the Secretaries-General and include discussions of actual, principled cancer relevant issues, long-term strategies and evaluation of activities.

Chairmen and Secretaries-General of the NCU members and invited guests participate, including representatives of ANCR – Association of the Nordic Cancer Registries.

6. An informal meeting is held in the middle of the period of the chairmanship for the chairmen and Secretaries-General with the purpose of exchanging experiences, and discussing on-going and actual cancer related topics.

§ 4 Chairmanship

1. The chairmanship is held alternately by the members for a 3-year period taking effect from the start of a calendar year.

2. The chairmanship of the NCU is responsible for the Union's secretariat function during the mandate period in relation to general matters and the scientific committee. The responsibility of the secretariat of advisory committees including a scientific committee may by specific agreement be transferred to another member organisation.

3. The society holding the NCU chairmanship co-ordinates collaboration between the Secretaries-General.

4. The chairmanship is responsible for planning a meeting for the Committee of Representatives during the late autumn of the last year of the chairmanship period, including preparation of an activity and evaluation report and for the chairman period.

5. The Chairmanship is responsible for planning an informal meeting to be held in the middle of the period of the chairmanship for the chairmen and Secretaries-General with the purpose of exchanging experiences, and discussing on-going and actual cancer related topics,

§ 5 Board

1. The NCU is governed by a Board comprising the Secretaries-General of the member organizations of NCU.

2. The Board has 3–4 annual meetings, usually in December/January May/June and September/October.

Specialists/staff members of the member organizations may participate and/or represent the members.

Main topics of the meetings include:

- All meetings: exchanges of experiences, decisions on strategic projects
- December/January meeting: approval of annual budget including allocation between strategic and scientific projects and report from the scientific committee
- May /June meeting: approval of accounts and annual report for previous year

3. The Board makes decisions concerning grants for strategic projects.

4. The Board decides after recommendations from the scientific committee grants for scientific projects.

5. Board may decide to establish committees and appoint committee members.

6. Decisions of the Board are taken by a simple majority of the Board members present. In the event of a tied vote, the NCU Chairman has a second, casting vote.

7. The minutes of the Board meeting are signed by the NCU Secretaries-General.

8. NCU contributes to the costs of the secretariat as decided by the Board.

§ 6 Scientific committee

1. The scientific committee comprises one member with scientific competence from each member country appointed by the NCU Board after recommendations from the national cancer societies.

2. The tasks of the committee are:

- to assess scientific grant applications, secure high scientific quality and formulate recommendations regarding the applications to the Secretaries-General for their decisions on grants
- to give consultation concerning strategic projects regarding research to the Secretaries-General for their decisions on grants
- to evaluate funded research and follow-up on the application of the results in the Nordic countries

3. The scientific committee is invited to an annual meeting and to the meeting for the Committee of Representatives held every third year.

§ 7 Finances

1. The NCU's funds are deposited and managed in a separate account by the cancer society which receives the funds that are placed at the disposal of the Union.

2. The annual budget, cost allocation between the members and balancing of the accounts are approved by the Board.

3. The NCU may receive grants and donations, from which it may pay out grants and provide support for strategic projects.

4. Decisions regarding the apportionment of any overheads not governed by the provisions of the statutes are taken by the Board.

§ 8 Signatories

1. The chairman of NCU and the Secretary-General of another society or two other Board members authorised by the Board may sign jointly on behalf of the NCU.

§ 9 Changes of statutes and dissolution of the Nordic Cancer Union

1. Any member of the NCU may propose changes to the statutes and these shall be sent to the Secretariat of the NCU and communicated by the Secretariat to all NCU members not later than two months prior to the meeting for the Committee of Representatives.

2. The chairman or two members of NCU may call for an extra-ordinary meeting for the Committee of Representatives with at least two months' notice stating the agenda.

3. The quorum of attendance required for changes of statutes or dissolution is at least three quarters of full members present or voting by proxy.

4. In the event of the dissolution of the NCU, any financial assets owned by the latter shall be distributed among its members in proportion to the apportioning index.

Statutes approved by the NCU Board on 10. December 2012 and will be effective 1 January 2013.

31.5.2016 - World No Tobacco Day (draft 04.05.16):

Call for plain packaging in the Nordic Countries.

In the Nordic Countries x people die each year from tobacco-related diseases.

Every year xxxx people in the Nordic Countries die as a result of tobacco-related diseases, and globally six million people die. Many of these die from cancer. The Cancer society's therefor unite today at the World No Tobacco Day in a common goal to prevent tobacco use among children and young people. We – The secretary Generals of the cancer societies in the Nordic countries - call for the introduction of plain packaging in all the Nordic Countries.

A tobacco free Norden

Tobacco use is a main cause for cancer. Today more than xxx millions in the Nordic countries smoke or use snus. The Cancer Societies in the Nordic Countries all work towards a tobacco-free society. In several of the Nordic Countries there has been made explicit statements for a tobacco free society. If we are going to succeed to make tobacco use history we need to look for new and effective initiatives.

We truly believe that plain packaging is an important demand reduction measure that will bring us closer to a tobacco free Norden.

Why Plain Packaging?

Plain packaging of tobacco products refers to measures that restrict or prohibit the use of logos, colors, brand images or promotional information on packaging other than brand names and product names displayed in a standard color and font style. In December 2012, Australia became the first country to fully implement plain packaging. And they have proven that plain packaging works[1]

International studies show that Plain Packaging of tobacco-products:

- are rated as less attractive, especially among young people
- is perceived as having inferior quality and taste
- makes health warnings more visible
- makes tobacco products less visible in public settings
- prevents smoking initiation and contributes to some extent to quit

Following the example of Australia, and more recently also countries like the UK and Ireland and France, we believe this will be the most effective new tool we have at our disposal in order to prevent young Nordic people from starting with tobacco.

Call for action

Guidelines to Articles 11 and 13 of the WHO Framework Convention on Tobacco Control (WHO FCTC) recommend that Parties consider adoption of plain packaging. A number of countries are in advanced stages of considering adoption of plain packaging laws. We now call for plain packaging in all the Nordic Countries.

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[1] https://www.cancervic.org.au/plainfacts/

NCU meeting 30.05.16
Agenda item 7.1 Cover letter.

European Coalition for Equal Access to Cancer Drugs - Declaration of Intent

Tekst til enclosure :

European Coalition for Equal Access to Cancer Drugs

Administrerende direktør Leif Vestergaard Pedersen og afdelingschef Jes Søgaard, begge Kræftens Bekæmpelse har deltaget i møde i den hollandske kræftforening 19.-20. april 2016 om forslag til European Coalition for Equal Access to Cancer Drugs

Den hollandske kræftforening havde inviteret 20 europæiske lande. I mødet deltog repræsentanter fra 5 kræftforeninger : Frankrig, Belgien (to foreninger), Luxembourg og Holland.

I mødet var også ECL – Association of European Cancer Leagues repræsenteret.

Deltagerne aftalte vedhæftede Declaration of Intent vedrørende European Coalition for Equal Access to Cancer Drugs **(attachment)**

5 nationale kræftforeninger og ECL er således med nu – det forventes at flere vil tilslutte sig.

Initiativet skal ses i sammenhæng med et lidt tilsvarende initiativ, som den hollandske sundhedsminister under hollandsk EU-formandskab har lanceret i samme uge.

Initiativet kan beskrives som en to-benet strategi i forhold til alle de svære spørgsmål vedr. økonomisk prioritering og patienters lige og uindskrænkede adgang til de lægemidler, som de og deres speciallæge finder bedst for dem.

Det ene ben er, at accessibility skal sikres for alle.

Det andet ben er, at accessibility fordrer affordability, men i stedet for at opnå det gennem økonomisk prioritering ... og dermed med patienterne som skjold eller gidsel, skal det opnås ved at gå ind i en kombination af dialog med og 'kamp imod' lægemiddelindustrien om deres prispolitik.

Leif Vestergaard Pedersen vil orientere yderligere om initiativet på NCU mødet

Sakari Karjalainen vil supplere med information om ECLs rolle i den kommende proces.

Indstilling:

Det indstilles,

- at initiativet drøftes
- at NCU medlemmerne opfordres til at tilkendegive eventuel tilslutning til initiativet

- DECLARATION OF INTENT -
EUROPEAN TASK FORCE FOR EQUAL ACCESS TO CANCER MEDICINES

CONTEXT

Both medical and technological developments have led to the increased provision of cancer medicines on the market. These improved and advanced treatments make it possible for cancer patients to survive or live longer with a better quality of life. Unfortunately, the number of people diagnosed with cancer is rising every year. The combination of increased cancer incidence in the population and new technologically advanced cancer medicines results in a situation where the total cost of cancer is rising which puts an unprecedented demand on healthcare budgets and/or makes treatment unaffordable for many cancer patients. There is a growing risk that affordability or pricing of the medication will become a deciding factor in a patient's cancer treatment in the hospital or in the doctor's office. This leads to instability and unpredictability; which is particularly undesirable to a patient who has received a cancer diagnosis. A political and social discussion must be held and as a result policy must be developed in order to ensure equal and affordable access to cancer medicines. Patients must be able to rely on receiving the best possible treatment to match their medical needs and optimise their potential for beating their disease.

CALL FOR ACTION

New cancer medicines offer new perspectives for patients with diseases that could hardly be treated or cured in the past. However, with these advanced cancer medicines come dilemmas concerning the extremely high cost and a rising number of cancer patients. Measures that are currently taken to guarantee the accessibility of new medicines and to limit their cost are no longer sufficient.

The sustainability of health care systems is also at stake. In our opinion, the pharmaceutical industry has broken the contract with society when setting exorbitant prices for new cancer medicines. Decisions related to pricing and reimbursement of cancer medicines are primarily the responsibility of national governments. Since the problem of access and affordability exists in many parts of Europe and beyond, it is necessary to join forces on an international level, exchange information and best practices and look for possible common solutions.

To assure the accessibility of innovative cancer medicines for all cancer patients, the countries of this task force have decided to join forces. This task force that will actively address the problems that threaten the accessibility of cancer medicines in an international setting, starting in Europe. We will work towards the following goals:

OUR GOALS

Our ultimate goal is to achieve equal access to medicines for all cancer patients in Europe.

Goal 1: The cancer societies of this task force state that all effective and innovative cancer treatments now and in the future should be accessible to patients. Patients cannot suffer from a dysfunctional system and/or unsustainable financial and pricing arrangements in the prescription of medicines.

Goal 2: Medicine prices should be sustainable and proportionate to real cost of research and development and added therapeutic value. In that respect an open, transparent and continuous dialogue with the pharmaceutical industry is needed. Knowledge and information must be shared internationally and co-operation must be sought after.
Goal 3: Cancer medicines that have a distinctive therapeutic added value should reach patients in a timely manner, in the safest way and at affordable prices. The patients should be fully informed of the possible benefits and harms.
Goal 4: Cancer societies in Europe should work together to get and keep this issue on the national and European agendas of politicians, policy makers and the pharmaceutical industry
Goal 5: Patients should at all times be involved in the decision-making process (eg. joint decision making concerning policies as well as treatment process).

Signatories to this declaration

ECL
Association of European Cancer Leagues

Association of European Cancer Leagues

DUTCH CANCER SOCIETY

KWF Kankerbestrijding, the Netherlands

Kræftens Bekæmpelse

Kræftens Bekæmpelse, Denmark

Kom op tegen Kanker

Kom op tegen Kanker, Flanders

LA LIGUE CONTRE LE CANCER

La Ligue contre le Cancer, France

Fondation Cancer
Info · Aide · Recherche

Fondation Cancer, Luxembourg

NCU meeting 30.05.16.

Agenda item 8.2

A few questions that could guide our discussions.

1. What are the main hindrances for implementation that you perceive?
2. What is the best way to ensure continuous political support –e.g. between elections?
3. What is and should be the role/involvement by stakeholders and cancer leagues in your country in the cancer plan process, - from developing to evaluating?
4. Does you cancer plan reflect psychococial issues andtheir relevancy adequately?
5. How is your cancer plan coordinated with other governmental strategies e.g. health, tocacco...and to what extent is it integrated with aspect of the health care services?
6. Is the financial comittment strong enough and nailed down?? Is it broad and general, macro financing, or is it down to more practical objectives?
7. What woudl you like to see as an improvement or change in the next plan?

NCU meeting May 30th 2016

Agenda item 9.1-cover letter

To the Board of the Nordic Cancer Union

The opportunities for increased cooperation regarding cancer screening have been mentioned at NCU Board meetings, and seemingly there is an interest to explore further the possibilities of economics of scale in this regard,- and whether effectiveness and success of the Nordic screening programs can be improved and thus should be supported.

A detailed proposal for a strategic project (with budget requirements) for increased collaboration in the Nordic countries on cancer screening might be of interest to the members of the Board of the Nordic Cancer Union. If that is the case, the Board might want to decide on the next steps, and perhaps start with learning more about the ideas for NORDSCREEN presented in the following brief, by inviting those in charge to our meetings.

Reykjavik, 20. maí 2016

Ragnheiður Haraldsdóttir

NCU meeting May 30th 2016

Agenda item 9.2

NCU and screening for cancer in the Nordic countries

-some points to consider

The question has been raised whether the Nordic Cancer Union has a role to play in strengthening collaboration among the Nordic countries in screening for cancer.

Cancer screening programs vary substantially among the Nordic countries (e.g. as to what age groups are screened and how often). Limited formal collaboration exists among those involved in the various screening programs. An opportunity for learning more from each others practices should be explored.

The cancer societies of the Nordic Cancer Union likewise have very different roles to play in relation to cancer screening programs in their respective countries. In some countries the cancer societies are responsible for screening program organization and implementation, while other are mainly concerned with e.g. research and patient information.

Similar differences also exist when other aspects of the work of the NCU member countries are compared. Thus, the cancer registries are in some cases run by the cancer societies, while in other countries the involvement is more limited. This has not hindered the cancer societies in supporting the registries for decades, and no plans have been voiced to change that.

In the recently adopted (February 2016) strategy for strategic projects the NCU Board emphasizes the added Nordic value of supported projects, aiming at improving the situation regarding cancer in the Nordic countries primarily. The Board has also decided that ideas for projects should mainly come from the Board and that the Board thus should initiate programs and evaluate their value for funding appropriateness.

The NCU has dedicated 250.000 Euros to strategic funds annually. Available funds are currently appr. 150.000 Euros for 2016 and the same amount for 2017.

Screening for cancer in the Nordic countries is in some ways advanced and could lead the way internationally. New Nordic initiatives in finding cancers at early stages and/or

new technology for screening are promising (e.g. first steps in measuring feasibility for screening for myeloma in Iceland, technical and methodological advances in screening for urinary tract and prostate cancer by developing home urine tests in Danmark) and could lead the way for new approaches.

A great example and an outstanding model to learn from could of course be the collaboration of the Cancer registries through ANCR, which has been very successful for decades. Some piecemeal extracts from the ANCR and NORDCAN websites follow for clarification:

> *The object of the Association is to provide a continuing, organized framework for the activities of the Nordic cancer registries to facilitate exchange of both scientific and technical information, to contribute to the uniformity of definitions used by the registries, and to facilitate the organisation of inter-Nordic studies and studies proposed by international organisations and various groups of individuals.....The object of the Association is to provide a continuing, organized framework for the activities of the Nordic cancer registries to facilitate exchange of both scientific and technical information, to contribute to the uniformity of definitions used by the registries, and to facilitate the organisation of inter-Nordic studies and studies proposed by international organisations and various groups of individuals.*
>
> *The aim of the collaboration was to compare the cancer incidence rates in the countries and to use that comparison in order to find out factors that explain the differences. It was realized that technical factors, definitions etc. also play an important role, and therefore a lot of attention was focused also on standardization of definitions and practices.*
>
> *Over the years, extensive comparisons between the countries have been published..... .....These results have also been communicated in local languages to the Nordic and national authorities. In 2000 the registries had the NORDCAN (link til PC-Nordcan) programme developed, enabling easy access to basic cancer statistics .... The data from each registry is converted to a similar format facilitating comparative research on e.g. survival. The registries thus play an important role in monitoring the effects of cancer control planning in the Nordic countries.*
>
> *The Nordic collaboration has been seminal and provided a good model for international collaboration between cancer registries.... The high quality of the data, enthusiastic workers and scientists and the high synergy due to pooling of the efforts and the data has lead the Nordic cancer registry collaboration to achievements better than could be expected from any country with a population of over 23 millions.*

A model for increased cooperation in the field of screening can also be the research collaboration initiated under the leadership of J. Dillner and supported by NORDFORSK. NIASC, however, has a much broader role in e-health, and thus screening is not it´s only priority. According to Dr. Dillner, *the overall objective of the NIASC is to develop eScience tools that can improve health and the social preconditions to health. One major objective is to develop and refine algorithms to assess risks of breast, prostate, colorectal and cervical cancer, which may ultimately lead to better cancer screening programmes.*

"There is a need for Nordic synergy in this field, particularly when it comes to training and mobility," continues Professor Dillner.

According to information from Dr. Nea Malila, the Cancer Society of Finland, a new project is underway, also in collaboration with Dr. Dillner. The NORDSCREEN project aims to create a cancer screening platform with similarities to NORDCAN. This work has just begun, but maybe with this collaboration other activities within the Nordic countries would be possible, e.g. trying to identify potential barriers in screening and harms and benefits related to screening,-according to Dr. Malila. One important aspect is to distinguish organized screening and voluntary testing (wild screening). Another important task could be the evaluation of quality of life which relates both to cancer screening and survivorship from cancer.

There are certainly numerous ways of initiating further collaboration in the Nordic countries in the field of cancer screening, e.g. supporting a screening conference (as has been suggested at NCU Board meetings), formulating an exploratory project with representatives from the Nordic countries, laying the groundwork by mapping the current practice (see the comparisons of cancer plans by EPAC) ,initiating a roundtable discussion with two or three members from each country, preparing a summer course modelled on the summer school in epidemiology, -and so forth and so on.

Here, it is suggested that the first step is to invite Dr. Dillner and some experts with him to our next NCU Board meeting in Finland to hear from them what their plans are and to learn more about their ideas for future collaborations. In addition, the Board may want to decide that some members of the Board take the responsibility of planning for this further and present their ideas also at our next meeting.

Reykjavik, May 18th 2016

Ragnheiður Haraldsdottir

NCU styrelsesmøde Reykjavik 30/5 2016

Dagsorden pk 10. Status over "avoidable cancer" projektet (NORDCAN projektpakken).

Det sidste delprojekt i NORDCAN projektpakken er gennemførelse af beregning af kræfttilfælde der kan undgås i de nordiske lande gennem målrettede forebyggelsesindsatser. Projektet er en opfølgning med nyeste data på KIN (Kreftbildet i Norden) projektet fra 1997 hvor de største risikofaktorer for kræft blev kortlagt i de Nordiske lande efter nøje litteraturgennemgang og vurdering af deres vægt i fordelingen og andelen af kræfttilfælde i år 2000 og publiceret i APMIS samt i Tema Nord (Nordisk Ministerråd) og en populær udgave af NCU.

Siden er de fleste informationer (incidens, mortalitet, prævalens, fremskrivninger og overlevelse) der var indeholdt i KIN projektet blevet tilgængelige genne årlige opdateringer i ANCR/IARC/NCU softwareprogrammet NORDCAN. Vurdering og fremskrivning af effekt af forebyggelsesindsats (Avoidable cancers) er en viden der aktivt kan bruges i kræftforeningernes forebyggelsesvirksomhed – politisk (regulering, lovgivning), kampagner, interventioner, oplysning. I begyndelsen af dette århundrede blev der i et EU støttet projekt under Hollandsk ledelse og deltagelse af de nordiske lande samt kræftforskning centret IARC udviklet analyseplatformen PREVENT. Den blev testet mod andre statistiske metoder og fundet egnet som analyseværktøj for de nordiske data.

En arbejdsgruppe med kræftepidemiologiske repræsentanter fra alle Nordiske lande blev dannet og i august blev Therese Andersson fra KI – Stokholm ansat til at gennemføre analyser og rapportere. Hjælp til vurdering af risikofaktorernes betydning hentes fra eksisterende litteratur og forekomsten af risikofaktorerne i befolkningerne i Norden og muligheden for at intervenere og hvor lang tid der vil gå før en effekt kan ses bliver estimeret ved hjælp af fagprofessionelle fra forebyggelsesmiljøerne.

Den første risikofaktor hvor analyserne er gennemført og hvor den videnskabelige artikel indsendes til peer review omhandler overvægt og fedme. Den næste risikofaktor der arbejdes med intensivt og som forventes analyseret og beskrevet videnskabeligt forventes i slutningen af august.

Hans Storm vil give nogle endnu fortrolige oplysninger om resultaterne fra første analyse mhp. kræftforeningernes vurdering af hvilke initiativer der bør iværksættes for at nedbringe riskofaktoren og derigennem spare liv.

NCU meeting May 30th 2016

Agenda item 11 cover letter

Cancer and immigration in the Nordic Countries

At the meeting of ANCR and NCU boards in Denmark in September 2015 there was a session on immigrants and cancer in the Nordic countries. It became clear that although those present during the presentations and discussions saw this as an important issue that should be taken up for further consideration in the Nordic countries, very limited information was indeed available.

As the legislation regarding documentation and registration varies greatly between the countries, it also became apparent that a Nordic perspective or comparisons would be difficult to construct.

Despite these observations, it was considered of value to work further on these issues, and an emphasis on research in this field was suggested as a first and most feasible step.

Thus, the idea was to start to prepare research proposals, and then to continue the discussion under the auspices of the ANCR.

In order to shed some light on what has been done since the aforementioned meeting, Laufey Tryggvadottir, director of the Icelandic Cancer Registry, contacted those in charge of the registries in the other Nordic countries. Due to the reasons above and other, only limited work has been done so far.

Laufey will briefly share her information and observations with the Board of the NCU.

Reykjavik, May 23rd 2016

Ragnheiður Haraldsdottir

Laufey Tryggvadóttir

NCU meeting May 30th 2016

Agenda item 12 cl

Cancer research and genetics in Iceland

The chairman of the NCU scientific committee, Dr. Þórunn Rafnar, will briefly introduce research on the genetics of cancer conducted at deCODE genetics (http://www.decode.com/research/). The presentation will highlight some of the most notable results coming out of the program and touch upon the potential clinical applications of the findings.

Following the presentation, there will be time for questions and discussion.

Reykjavik, May 23rd 2016

Ragnheiður Haraldsdóttir

NCU 30/5 2016
Agenda Item 14.1

ANCR & NCU Symposium 2016

in Gustavelund, Tuusula, Finland, 30 Aug – 1 Sep 2016

Draft program

Tuesday 30 Aug

- 12:00 ANCR Board meeting
- 14:00 Presymposium workshop 1 on coding issues (see below)
- 14:00 Presymposium workshop 2 on IT-related issues (see below)
- 18:00 Barbeque party event for those who come before late evening

Wednesday 31 Aug

ANCR Symposium starting at 9:00

- Guest presentation: 10 years of Cancer Registry activities in Belgium
- Oral and poster presentations on topics related to cancer registration, descriptive research and analytical research on aetiology of cancers
- Social-cultural-sportical program
- Sauna & swim
- Gala dinner under palm trees

Thursday 1 Sep

NCU Symposium starting at 9:00 and ending with lunch at 13:00

- Presentations invited by the NCU
- Offered Cancer Registry presentations on NCU-relevant topics: NCU-funded projects, interventions/screening, "quality" registers, biobanks

Registration to the symposium is now open at this link.

The deadline for registration and abstract submission (see instructions below) **is 20 May 2016.**

If you like to book a **hotel room** at the Symposium Venue, please send an email to **the Hotel Gustavelund (reception@gustavelund.fi) and mention booking code: ANCR 2016. The rooms are kept for us until 1st of August. Please do your booking before that!**

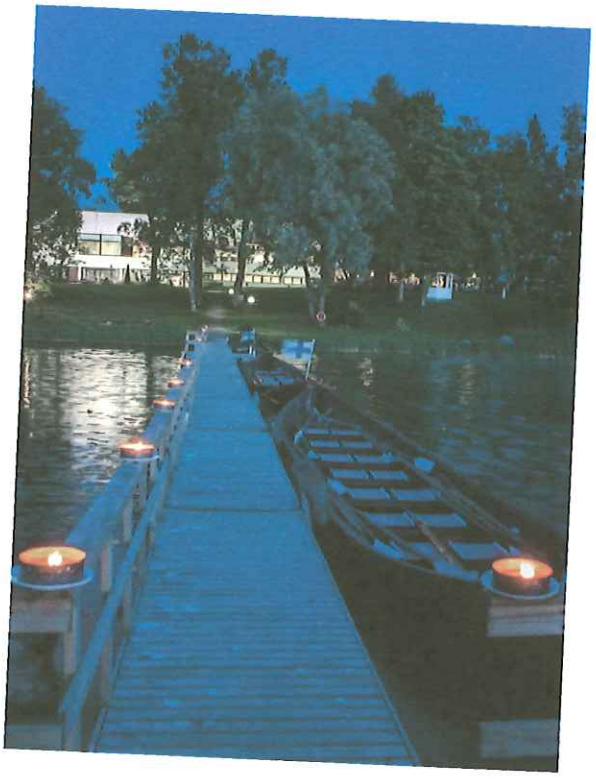
Room prices per night: Single room 99 €, Double room 130 €, Superior single 129 €, Superior double 159 €.

Questions: Eero Pukkala, eero.pukkala@cancer.fi, phone +358 50 300 2413

ANCR & NCU Symposium 2016

Abstract instructions

- Abstracts may be submitted for oral and poster presentations
- Abstracts and presentations will be in English
- Abstracts will be accepted in MS Word (doc, docx), rich text (rtf) or text only (txt) formats
  - Please name the file starting with the surname of the first author
- Abstracts should include:
  - Title
  - Author(s), underline presenting author
  - Institute(s)
  - Max 250 words of text
  - Word "POSTER" if you prefer poster presentation
- Please send the abstract not later than in **May 20, 2016** to abstracts.ancr2016@cancer.fi
- The scientific committee will evaluate the abstracts before June 17, 2016, and let you know about acceptance and format of presentation



ANCR & NCU Symposium 2016

Presymposium Workshop 1 (30 August from 14:00 to about 17:00):

Current challenges in cancer coding

Examples of topics that may be discussed are listed below. Please come with other suggestions of topics either in advance (mail to juho.nurmi@cancer.fi) or during the workshop.

- case reports; challenging cases
- multiple primaries in different topographical sites (e.g., colorectal cancer C18-20)

Urinary tract C65-C68
- urothelial neoplasms – urinary papilloma – changes in time; new WHO – urothelial papilloma is benign
- multiple neoplasms – same time – different time – different behavior of tumour at the same
- how your registry deals with

Haematological malignancies
- tranformations, how do you code
- multiple neoplasms
- ICD-O-3 vs. WHO classification vs. ENCR 2012 recommendations

Teaching / acquainting of a new coder
How to acquaint a new coder? What kind of knowledge should a new coder have before starting cancer coding (education etc.)? How to organise the work; should it be done by sorting out the organs/topographical sites/ or by diagnoses/cancer types/PADs? How to teach effectively? How to find latest news and to use reference sources?

Presymposium Workshop 2 (30 August from 14:00 to max 17:00):

Cancer Registry IT

Examples of topics that may be discussed are listed below. Please come with other suggestions of topics either in advance (mail to kaius.perttila@cancer.fi) or during the workshop.

Big data and Cancer Registries – open discussion regarding the need of a big data approach for cancer registries' future data collection.

- **why** would we want big data, including unstructured and non-required data?
- **will** the collection of big data affect the official mission of cancer registries?
- **who** will, or might, need this data?
- **what** is it going to be used for?
- **when** will there be a need for receiving/processing/providing the data?