CANADIAN LUNG ASSOCIATION/ CANADIAN THORACIC SOCIETY NATIONAL MEETING NATIONAL RESPIRATORY RESEARCH AGENDA

Meeting Report

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Fort Garry Hotel
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1. Background and Introduction

The Lung Association works at the national, provincial and community levels to improve and promote lung health. The Canadian Thoracic Society (CTS) is the medical section of The Lung Association. It collaborates and supports the respiratory community by providing leadership, research, education and advocacy. Through Research Grants, Fellowships and Team Grants, the CTS funds leading edge medical research in Canada in order to find treatments, and ultimately a cure, for lung diseases. A collaborative committee was struck to create a National Lung Health Framework that would serve as a catalyst for change by building partnerships, sharing best practices and identifying gaps and opportunities in the respiratory health community. This framework was the impetus for building a stronger research agenda. During an initiative organizing meeting in June 2009, an Interim Research Steering Committee was formed to advance this initiative.

To this end, the Canadian Lung Association (CLA) / Canadian Thoracic Society (CTS) convened a National Workshop in order to consult with various stakeholder groups with a goal to strengthen its research program and create a national respiratory research agenda. Over this one-day workshop, presentations were made to provide participants with a background and context of CTS, an update on the current status of Respiratory Disease in Canada, the British Experience as exemplar of raising the profile of respiratory research, and finally, a case study demonstrating effective partnerships. The meeting concluded with the elaboration of challenges/opportunities, a Preferred Future for research, Key Result Areas, and recommendations that would help CTS take the first steps to establishing a stronger research agenda. This report summarizes the discussions that took place.

The Objectives of the workshop were to:

- To encourage national networking and partnerships;
- To evaluate the current status of respiratory health research in Canada;
- To create a National Respiratory Research Agenda;
- To develop a realistic action plan to increase funding for respiratory research.

Introductions

In the CTS National meeting, there were 52 participants in the room, representing 14 Universities, and numerous associations, provincial and federal funding organizations, hospitals and scientists across Canada. (See Appendix B). Participants introduced themselves and shared their expectations of the workshop. These included a desire to identify strategies to raise awareness of the importance of respiratory research, both to the public and the main funding agencies, to develop funding sources other than Canadian Institutes of Health Research (CIHR), to expand partnerships to include industry, to get a firm commitment to follow-up on actions decided, to assess the likelihood of success, to make research saleable, and to identify the possible barriers from the past so we can move forward with a better plan. (A full list of the expectations can be found in Appendix C).

Opening Remarks
Denis O'Donnell, President, Canadian Thoracic Society

Denis O'Donnell began the meeting by welcoming the participants and recognizing that similar interests were bringing them together. He talked about the recently approved new structure of CTS, and the 13 member Board of Directors.

Dr. O'Donnell challenged the group to verify the perceptions of research, and their truth or fictional base. He said that in order to effectively develop a realistic research agenda, it is important to build it on a basis of fact. He reviewed a series of perceptions that were gathered from a survey of research institutes across the country. The self-reported

results indicated that researchers believe: that respiratory research is grossly under funded, that clinician-scientists in respirology are in danger of extinction, that few graduates of respirology are opting for careers in clinical research, that research training is no longer required for an academic position, that funding agencies favor basic over clinical research, that the application process for CIHR is extremely cumbersome, that the Respiratory Panel is dominated by basic scientists, that the risk of failure for the clinical researcher is very high, that funding opportunities for independent clinical researchers are limited, that many well trained "mid-career" clinician scientists no longer run active research programs, that young researchers are not specifically targeted for support, that most clinical researchers in academic institutions are primarily by the Pharmaceutical Industry, that the Respiratory component of the CARDIO-respiratory node of the CIHR is disadvantaged, and that Canadian respiratory researchers consistently under-produce on the world stage.

Dr. O'Donnell offered some data which in some cases supported the perceptions, and in some cases refuted them. The information presented came from 15 institutes, country wide. He noted that research output from 2003-2009, when adjusted for GNP and population, showed that Canada was in first place in the number of impactful articles produced; this dispels the myth that Canada under performs internationally. When considering the disappearance of the clinical scientist and the diminished activity of the mid-career researcher, the data indicated that there were only three institutes who had more than eight clinicians with 50% of their time protected for research. The belief that fewer graduates are opting for a research career was substantiated by the fact that six institutes have no graduates committed to a career in research. The data presented showed that the majority of clinical researchers are primarily funded by the peer-reviewed federal/provincial process, with only three institutes being heavily funded by industry.

Dr. O'Donnell continued by saying that increased collaborative research, transitional research, increased involvement of respiratory trainees in research, and the development of junior faculty member were all major short term goals. Long terms goals were identified as: enhancing clinical research programs, a dependence upon the funding model for Division/Dept of Medicine, an increased ability to recruit individuals with substantial protected research time, a focus on Interventional Research, an expansion of ICU-related respirology research, an increased focus on Aboriginal lung health, and finally, a focus on building research intensity, productivity and output. He identified a lack of funding and infrastructure, barely adequate manpower, and the challenges of proper training, as serious barriers to successful Clinical Research Programs.

He said he hoped that they would come together as a group to work towards developing a realistic action plan that would address these challenges and lead to the successful implementation of a New National Research Initiative.

Questions, answers, and comments revolved around the following topics:

- **Silos are not an effective way to engage in research.** A team approach to research is more powerful than a siloed approach. The implementation phase of the research is more effective if team members have been involved from the beginning of the project.

- **Importance of having a clear definition of clinical research.** Some felt having a definition of basic and clinical research was essential. It was suggested that a broad definition of clinical research could be that it "requires interaction between a clinical investigator and a patient". There was a question as to whether it was necessary to define terminology. Some suggested that it was more important to think about the research rather than the researcher, and how it could be integrated and translated into useful clinical applications.

- **Practicing clinicians have had a radical shift in culture.** It was noted that there has been a radical shift in culture where the clinical deliverable has overshadowed the importance of active research. As a result of this pressure, research initiatives have been decreasing in the community.

2. Presentations

A. Current State

Three speakers were invited to shed light on the current state of respiratory research in Canada. Their presentations underlined the need for greater emphasis on respiratory research and the procurement of funding in this area.

Burden of Respiratory Diseases in Canada
Jessica Evans, Epidemiologist, Public Health Agency of Canada (PHAC)

Jessica Evans began by providing a picture of respiratory disease manifested across all ages and segments of the Canadian population. She said the priority in their work is in asthma. She outlined the prevalence of respiratory disease (except sleep apnea) including those caused by tobacco, asthma, chronic obstructive pulmonary disease (COPD). These respiratory diseases afflict all ages and segments of the population and can have a major impact on the individual, the community and the health care system. She outlined a number of pertinent data points that support the need for increased resources to be devoted to respiratory research in order to help relieve the burden of lung disease. They were:

- Five serious respiratory diseases affect over three million Canadians – asthma, COPD, lung cancer, tuberculosis and cystic fibrosis with Asthma showing up as the fifth most prevalent chronic condition;
- COPD is responsible for 50% of all respiratory deaths across Canada;
- The number one preventable factor associated with respiratory disease is smoking cigarettes. Although there has been an overall decrease in smoking, the highest numbers are being reported among young adults and aboriginal people making our youth and native peoples most vulnerable to respiratory illnesses;
- 16% of young children are afflicted with asthma, making them particularly vulnerable;
- Although the prevalence of Asthma in adults has levelled off at about 8%, the trend is increasing in older women;
- Estimates for COPD in adults over 35 are greater than expected, with national levels estimated at 8.5%; aboriginal rates even higher;
- Tuberculosis rates in Canada have decreased over time with an incident rate of 4.8 per 100,000.
- Lung cancer is the leading cause of cancer deaths in men and women representing approximately 1 out of every thousand people in 2006; increasing mortality in women is predicted;
- People with Cystic Fibrosis are living longer, and the mortality rate in the young is decreasing;
- Mortality rates from respiratory distress syndrome (RDS) has decreased dramatically from 1987 to 2004 although it is still the leading cause of death for infants up to 12 months;
- Recently people waiting for lung transplants have increased steeply, while the number of transplants performed has decreased.

Federal Research Funding and Opportunities
Dr. Peter Liu, CIHR, Institute of Circulatory Respiratory Health (ICRH).

Dr Peter Liu began by saying that the timing for mounting a national effort and developing a strategic plan for respiratory research was excellent because CIHR and the Institute of Circulatory and Respiratory Health (ICRH) are in the process of developing their 5 year research strategic plan. He said the strengths of institute are its people who work closely with the community. He said that the burden of chronic disease is great, with 85% of healthcare funds being dedicated to early and late chronic disease management. In order to address this problem, the CIHR Funded

Respiratory Research Strategy is to examine more upstream contributing factors such as environment and genetics, and to work more closely with knowledge experts who will help translate research findings into practice.

He outlined some of the current projects that are being funded in these areas, as follows:

- Indoor Air Exposures, Genes, and Gene-environmental Interactions, $6M (with partners);
- CIHR RX & D. Collaborative Research Program, $435,000 (partnership program);
- Gene-environment Interaction in Respiratory Disease, $2.l7M;
- Canadian Tobacco Control Research Initial, $7M. (31 projects);
- Gender and Sex Determinants of Respiratory Health, $1.15M;

Dr. Liu stated that the CIHR is building interdisciplinary capacity through projects such as the Strategic Training Programs in Health Research (STIHR) and the Ultra Rapid Response Grants directly for the H1N1 pandemic in Canada.

He outlined the following facts about CIHR/ICRH funding and gave examples of funded programs and funding opportunities.

Increased funding for CIHR / ICRH grants and awards (personnel support). From 2000-2009, the CIHR Respiratory funding increased from $12.0 M to $30.0 M representing an increased of 150%. Awards have remained constant. Total funding to ICRH has increased from $15.0 M to $35.0 M in the same time period; although it is still a distant second to Cardiovascular funding.

Clinical research funding has continued to increase. Data shows that clinical funding has increased from $20.0 M in 1999 to $100.0 M in 2007. Basic research has tripled in funding, growing from $100.0 M in 1999 to $400.0 M in 2007. This challenges the perception that basic science is being "crowded out". Clinical research has grown, although not as much.

Examples of recent priority programs that are well reviewed, successful and clinical fitting are:

- Clinical Imaging Team Grants, $2.1M;
- Alternative Radiopharmaceuticals for Medical Imaging (Federal) $195,000;
- Mexico-Canada Joint Health Research Program in TB, $160,000;
- Basic Research and Therapy – Breathe Initiative (collaboration with the CCFF), $745,000.

Examples of current programs being rolled out are:

- Sleep: circadian impact on respiratory and cardiovascular diseases, metabolism and obesity, and means of diagnosis, treatment and prevention;
- Psychological, social, behavioral and environmental determinants of at risk behaviour for chronic disease, and means of effective interventions;
- Technology for diagnostic and therapeutic advances, including imaging technologies for early detection of disease;
- Operating Grant: Alternative Radiopharmaceuticals for Medical Imaging.

Upcoming funding opportunities coming from the strategy board were identified as:

- Looking at biomarkers for chronic disease, including genetic prometric, phenotypic markers for prevention diagnosis and guidance for therapy;
- Ideas that involve multiple disciplines.

Funding for Canada Research Chairs. Canada Research Chairs (CRC) have a significant amount of the funding allocated to them so it is important to understand the funding process and to solicit the support of the Institute.

Building Respiratory Research Capacity. Respiratory Personnel Awards have slightly increased from 2000-2001 to 2008-2009 from $3.0 M to $3.8 M. More importantly, the data shows a larger portion (approximately 40%) of this funding is being dedicated to new investigators and Doctoral Awards; this challenges the perception that new investigators are being overlooked.

Top priorities of a successful research program should be to invest in researchers with bright ideas and those who have initiative.

Dr. Liu concluded by describing the best way to acquire research funding is for the clinical-scientists to ensure the support of the host institute and department within their universities, and be mindful of the following recommendations:

- Ensure adequate start up funds & infrastructure;
- Implement a mentorship and buddy system;
- Protect time for at least three years of the researcher's career;
- Get access to clinical research resources and basic science state of art core facilities;
- Ensure external/intramural salary support;
- Link with national and international networks for support;
- Aim for excellence.

Research Funding and Priorities in Canada
Anne Van Dam, Canadian Thoracic Society (CTS).

Anne Van Dam began her presentation by describing the CTS structure, and by characterizing the Lung Association's Research Programs available through the Canadian Thoracic Society and the Provincial Lung Association Research Programs. She said that the CTS/ National Research Programs are funded by the Provincial Lung Associations though annual research assessments totalling $500,000. This funding is split between the CTS Fellowships, Studentships and Partnered Fellowship Awards (with CIHR and Industry) representing 70%, and the Canadian Respiratory Health Professionals (CRHP) grants and fellows representing 30%. She talked about the need for a bold research action plan in order to capitalize on these funding opportunities.

National Research Programs: Canadian Thoracic Society Research. As exemplar, in 2009-2010 there were 17 applications received for CTS Fellowship awards, and 16 for the Studentship awards. Of the Fellowship awards, 11 were fundable and two were funded for $115,000. Of the Studentship awards, again 11 were fundable and two were funded for $90,000.

Canadian Respiratory Health Professionals (CRHP). Through Grants, Fellowships and Knowledge Translation Awards, the Canadian Respiratory Health Professionals funds research up to $150,000 per year. There has been a decrease in the number of funded awards from 18 to 7, and a corresponding decrease in funding amounts from $183,000 to $85,000.

The National Grant Review is a peer review service provided at the national level for Provincial Lung Associations grant-in-aid competition. The numbers of Basic Science Applications are funded twice as often as Clinical Applications. Ontario, British Columbia and Alberta are the only provinces participating in this competition which fund approximately $1.2 M annually. The provinces are responsible for administering these awards. These numbers corroborate the belief that "funding agencies favor basic over clinical research". There is a drive to evaluate the program to make it more equitable.

Canadian Respiratory Guidelines (CRGC) has a strong focus on knowledge translation. Five active committees are working collaboratively to produce guidelines and tools that will help translate scientific discoveries into improvements

in respiratory care. The Canadian Respiratory Guidelines Review cycle is: Production (Jan-Apr), Post Production Planning (May-Jul), Dissemination and Implementation (Aug. – Sept.), and Evaluation (Oct. – Dec.).

Provincial Lung Associations Research Programs offer a variety of research grants, fellowships and professor fellowships, both peer reviewed and other.

There is a need for a bold research plan…

… because in 2008, respiratory illnesses was a leading cause of hospitalization at 40%, and 40% of emergency department visits;
… because annual costs are estimated to increase to over $170 billion by 2020;
… because respiratory diseases are the least funded areas in Canada, ex: representing only 3.9% of CIHR funding;
… and because Canada has some of the best respiratory researchers in the world.

Anne Van Dam concluded by saying that the CTS Interim Research Steering Committee is working in collaboration with CIHR – ICRH. The membership consists of: Dr. Shawn Aaron, Dr. A. Halayko, Dr. D. Goodridge, Dr. L. Lands, Dr. R. Leigh, and Dr. D. O'Donnell.

PANEL QUESTIONS AND ANSWERS: Jessica, Peter and Anne

After the presentations, participants had an opportunity to comment and ask questions. The following summarizes some of the key concerns and comments. (Details can be found in Appendix D).

Concerns and comments for Dr. Liu:

- **Concerning lack of funding for mid-level and senior investigators.** Three strategies to address this issue were suggested: 1. CRC is a political process so it is important to work with the Chairs and the institution to ensure that research is a priority. 2. Work with partners to develop Chairs for senior investigators. 3. Recommendations from the research community on solutions to this problem would be valuable.

- **Lack of funding for the burden of respiratory disease.** It is true that respiratory community has been languishing in terms of CIHR funding. A robust, competent, and innovative research community will encourage funding. The CIHR has included respiratory research funding in its strategic priorities.

- **Low profile for lung disease.** CIHR takes a neutral position, however it can present a strategy which is informed by the Lung Association's/ CTS recommendations. Where appropriate, CIHR can get the message to the public. A powerful and effective way to raise the profile of respiratory health is to engage a champion.

- **Criteria and decision making process for research priorities.** CIHR has a strategic planning process. First, the advisory board solicits input from the research community. They evaluate the capacity and then match the ability to deliver to the research capacity. There is a need to look at the dollars spent compared to the potential impact of the project in terms of scientific excellence.

Concerns and comments for Anne Van Dam:

- **Suggested strategies for accessing CTS funding.** Direction comes from the CLA board and research assessments received. It was suggested that investigators should leverage some funding with partnerships and corporate sponsorships. The provincial funding agency needs to develop a strategy for research in order to get the message out that more research is needed.

Concerns and comments for Dr. Evans:

- **Better research data.** PHAC is expanding data sources to include more than self-reported information. They are using provincial data and information from the community to increase the data sources. *Comment:* Encouraging these partnerships to build on existing research and to help define a future research direction would be value-added.

- **Addressing the lack of appetite for research.** This lack of appetite is not unique to respiratory research. It is important to identify and encourage research trainees early in their career. Equally important is to have leadership commitment and a culture that transmits passion and persistence to researchers and future researchers.

The British Experience
Dr. Stephen Holgate, MRC Clinical Professor

Shawn Aaron, CTS Co-Chair, introduced Stephen Holgate as an Medical Research Council (MRC) Clinical Professor, the Chairman of the Science in Health Group, and a recognized expert in the area of respiratory health. Dr. Holgate began his talk by giving the historical context and development of the respiratory community, including the influences of Tuberculosis, air pollution and smoking, and lung cancer, which were key motivators for scientists engage in respiratory research and to join with Public Health agencies to improve lung health. He continued by describing the U.K.'s experience and journey in creating a resilient research agenda.

Dr. Holgate noted that research is changing foci and there is a demand for evidence-based medicine, a need to harness the molecular revolution and understand the complexity of disease, and a need to capitalize on funding arrangements. More professional training in research methods, involvement of patients in research, and research ethics and governance are all complex issues to be considered. Translation is also an important consideration.

He identified drivers for change that will maintain the highest quality of science in research: global competitiveness, investment in large scale science, the ability to anticipate and respond rapidly to the threat of disease, and career development.

Since 2005, funding in the U.K. has increased through the contribution of government and university. He said Sir D. Cooksey reported in 2006 that the majority of research was focused on cause and biological responses linked to disease and that there was an inability to translate this knowledge into patient care. The report ascertained that they needed to identify the gaps in translation and address them in order to move clinical study into patient care. To this end, the Medical Research Council (MRC) Comprehensive Spending Review (CSR) Settlement was increased by 30% since 2007, with specific allocations for the Office for Strategic Coordination of Health Research (OSCHR), for translational and public health research, and for collaboration with Technology Strategy Board (TSB).

A single integrated approach to Medical Research in the U.K. was developed and administered by a multi-disciplinary board. The MRC was asked to restructure to include a Translation Research Group which is responsible for ensuring that support for translational research is strengthened across all the MRC's research boards and for overseeing implementation of the MRC's new translational schemes. They developed a single broad based integrated strategy for UK medical research that included working with partners. One of the key areas was to form relationship with the charity sector because they are tuned into public need. They also wanted to get industry more actively involved.

Dr. Holgate described the MRC strategy for 2009-14 as being focused on choosing research projects that deliver, translating research into health care, going global and supporting scientists. He said the delivery plan and major foci of MRC activity over this period will be to work with the multidisciplinary strategic teams to close the gap between discovery and delivery. This will be accomplished through the three special schemes which are the Developmental Pathway Funding Scheme (DPFS), evaluation and assessment mechanisms, and industry partnerships.

Dr. Holgate outlined the key points for the development of successful health research programs were to:

- Maintain strong basic science but encourage more translation;
- Establish Multidisciplinary Centres;
- Enhance capacity building in under-researched fields (basic and clinical training fellowships, career development awards, clinician scientist awards, senior fellowships);
- Establish strong and purposeful partnerships with industry, charities, government departments, and overseas.

In the area of respiratory disease, Dr. Holgate said that, similar to Canada, the U.K. disease burdens of Asthma and COPD are high and they are chronically underfunded. Because of this situation, it is necessary to have an integrated approach to lung disease. He described the U.K. model that helped in raising the profile of the UK Respiratory Research Strategy. This included selecting clinical trials, identifying impactful research questions, and using the following steps to move forward:

- Utilisation of UKRRC Members;
- Short list derived from long list of clinical trials/research questions using Delphi Technique, and create a list of priorities;
- Identify leaders to form a Clinical Trial Subgroup to work up protocol;
- Turn research question into a clinical trial;
- Apply for funding;
- Involve appropriate Units.
- Other important steps were to identify those key to contribute, ensure trials are multi-centre and have adequate capacity for recruitment, and identify statistician interested in lung disease.

The organization achieved the following results in 2005: They produced regular newsletters, created a website, and produced a highlight notice at MRC which yielded an increase in the number and value of research awards. Other successes were the funding of 23 basic science studentships, and four new clinical training fellowships. From 2004-2008, there has been an increase in Respiratory Award funding by thirteen-fold for Research Grants and two-fold for Fellowships. Future plans of the UKRRC were outlined as: providing support for a Research Facilitator, to develop a web-based prioritisation exercise, to enhance research activity in lung cancer, and to organize a National Research Fellows annual meeting to express appreciation.

Questions and Answers for Stephen Holgate:

Participants asked questions about Dr. Holgate's presentation. A summary of the key points is presented below. (See Appendix E for the full discussion.)

- **Seek support for lung health research.** Solicit support from the lung community first. Get the public involved by lobbying at the government level. Having a report with priorities including multiple agencies and speaking with a single voice will have a powerful impact. If the Institute is doing good work, industry will support it. There are very influential people who supported this event. Look at the resources surrounding your organizations.

- **Priorities in establishing the distribution of funds.** Investigators work from the heart and should not be constrained. Pure scientists need to be protected. A consortium can mount grant proposals based on the scientists' interests. Encourage interest in young clinicians early at the university level before they reach PHD by using such programs as the academic clinical fellowships.

- **Pros and cons of centres versus virtual sectors.** The networks and centres are analogous to the hub and spokes; both serve an important function. It is important to concentrate efforts in order to compete at the internal level. Ex: Holland priorities exercise where universities successfully competed together.

- **Taking advantage of the PHAC relationship to move forward.** The decision on how to capitalize on research resources is part of the agenda in this meeting. Being able to use the consensus in the room to identify four or five agreed upon actions to move the research initiative forward will go a long way to achieving the group's goals. A shift in focus to growth rather than deficit will help motivate people.

- **Promoting and nurturing research.** It is very important to change the mindset / concept that people do not want to do research. People are very interested in research, especially when investigators experience top class people who empower them to move forward. This confidence and passion empowers them to apply for funds they may not normally apply for.

- **Pitfalls to be avoided.** Avoid "Taking your foot off the accelerator". Once actions are taken and the momentum builds, it is important to sustain and maintain the effort, and to nurture the youth in order to keep the momentum moving forward.

- **Influencing charities to re-examine themselves and their structures?** Charities are bodies that the public support; their structures are different from government organizations. They are interested in the patient's improvement and at moment, charities are the only interface with the public. Charities can use patient base effectively to prioritize lung heath issues. In exchange for their support, you can offer to help them with their peer review process.

Partnerships

Partnerships – The Essentials
Dr. Arnold Naimark, University of Manitoba

Dr. Naimark was introduced as an eminently qualified national leader in respiratory research who is currently a Professor of Medicine at the Centre for the Advancement of Medicine, and is Dean emeritus and former President of Medicine at the University of Manitoba.

Dr. Naimark reflected on the ambiguity of terminology when referring to clinical research and translational research. He said that there were many types and modes of partnerships and it would be important to carefully articulate the partnership before entering into it. Being a way to organize resources, power or influence, partnerships can be strategic or tactical. He presented a Treasury Board Study which identified alternative models of partnerships involving government, academia and industry which would give helpful guidelines to the Canadian Lung Association. The framework proposed was:

1. Articulate the overarching goal (broad purpose) well.
2. Develop a general strategy for achieving the goal
3. Articulate specific strategies
4. Have measurable outcomes – sustainability can erode if not clear.
5. Build in governance and accountability requirements
6. Evaluating proposed (proposals) (critical success factors) partnership.
7. implementation of the plans
8. Performance assessments

He identified critical success factors with respect to partnership as: likelihood of success, strength of commitment of the parties, quality of the proposed management and accountability arrangements, strength of managerial and scientific leadership, clear indications of feasibility, impact, timeliness, sustainability, performance assessment are all important factors to making the partnership a success.

He talked about successful examples of partnerships such as: partnership against cancer, national institute of nanotechnology, the national networks of Centres of Excellence, the Canadian Centre for Agriculture Research in Medicine (CCARM), and the pre-competitive Applied Research Network.

Partnerships – Networks
Professor Éric Rousseau, Ph.D.

Dr. Rousseau, Chair of the Respiratory Health Network (RHN) scientific committee of the *Fonds de recherché en santé du Québec* (FRSQ) is a consortium of investigators working in the field of respiratory health research in Quebec. The objectives are: to provide funding for the development of strategic research initiatives; to help in the development of multidisciplinary research projects; to provide core facilities; to promote knowledge transfer; and to further training and recruitment of young investigators in the field of respiratory health. He said the RHN have members both inside and outside of the network. They have a single database used by five different centres to classify samples. They have been very successful with their COPD research group. With different clinical studies, they have successfully worked regionally.

He concluded by saying that the RHN is a dynamic research infrastructure aiming to assess the main respiratory issues. He said they have been creative and rely on a strong scientific research community. They have developed new tools and a positive cultural background in this field. They are currently applying for renewal and are interested in developing new collaborative opportunities across Canada and with research teams in the US.

Questions and Answers for Éric Rousseau:

- **Advantage and disadvantages of networks and centres.** There is a need for both virtual networks and centres because each serves a different purpose. It is important to decide the goal. The experience with Respiratory Health Network (RHN) has shown that some achievements that could only be made through the centre, and others could only be achieved within the network.

- **Funding for the RHN** comes from the partnership with the FRSQ. The Minister of Health requested that the networks be established. The RHN is required to demonstrate added value and effectiveness.

- **Comment on partnerships:** The partnership component needs to be built in at the front of any new network structures including an identification of who will use the research and how. The key to addressing translational issues is to develop capacity to do the clinical trials with the pharmaceutical company and make sure the information is being fed to the government and into the public arena.

3. Development of a Successful Respiratory Research Agenda and an Action Plan

The participants brainstormed five challenges/opportunities that would lead to a successful Respiratory Research Agenda. For each of these components, they developed a vision, and elaborated on Key Result Areas and Recommendations for Action. The results of these discussions are summarized below.

	1. Challenge/ Opportunity: Geography and Politics
Preferred Future	1. All provinces or regions have the equivalent of FRSQ and equivalent funding; ex: LHF, template / model to be customized by province; need data on Return on Investments (ROI); 2. National public web-based access to list of Canadian Researchers and research expertise (searchable) [product of NLHF] 3. Research investment alignment with national priorities funded provincially, undertaken by inter-provincial research teams, ex: Provincial thoracic society's and respiratory care society's are aligned with CTS/ CRHP; 4. Research opportunities are nationally accessible across universities, provinces, hospitals
Key Result Areas	1. Create a new province/ regional research infrastructure; 2. Complete development of the National Research Capacity Asset map; 3. National alignment of respiratory research priorities; 4. Ensure national accessibility to opportunities to participate in research.
Recommendations	1. Lobby government (where there is an election issue) and CIHR to effect introduction of provincial research infrastructure like FRSQ or MSFHR. Alternately , each provincial government could "top up" grants in this area scored high and funded by CIHR) 2. CLA/CTS complete web Research Capacity Asset map; 3. Dedicated initiative to define research priorities and fund them, ex: CIHR, Industry, Provincial non-profits; 4. Use CLA/CTS Asset map to identify and inform the whole community about research opportunities, and to hold networking, and information sharing workshops.

	2. Challenge/ Opportunity: Partnerships
Preferred Future	1. There are an agreed upon set of priorities for partnerships; 2. Partnerships are leading to new training opportunities and an increase in experts and excellence in research; 3. The National Lung Health Framework (NLHF) is facilitating knowledge sharing among all respiratory stakeholders to support provincial research strategic planning. 4. Industry actively partners in lung health research.
Key Result Areas	1. New training opportunities and increased capacity and excellence in research; 2. All provinces have a business case to go to their governments and partners; 3. Business cases are integrated with the National Lung Health Framework (to prevent competition for funding).
Recommendations	1. Do a SWOT analysis to identify gaps and understand the research partnership "landscape"; i. Work together to leverage funds to open up new opportunities for funding to address gaps; ii. Evaluate work. 2. Develop a forum of investors to discuss priorities and agree on leveraging opportunities; 3. Increase communication and coordination among leaders of provincial research strategies and between national and provincial strategy planners. 4. Create an online space where researchers are sharing data with each other and bio banks; 5. Use the NLHF as a tool for bringing stakeholders together and facilitating information exchange; 6. Draw on the UK model as an example for building successful research partnerships. 7. Use inter-provincial translational research networks; 8. Create and use a researcher's data base.

	3. Challenge/ Opportunity: Communication
Preferred Future	1. Common goals and priorities for a communication strategy are established.
Key Result Areas	1. Advertizing and marketing that focuses on lung heath communication.
Recommendations	1. Develop an advertising and marketing plan with communication experts; 2. Initially, organize the research community around the communication strategy, and then involve industry; 3. Refer to the Lung Health Framework to seek funding for the advertising; 4. Agree on a common message and then craft the message and the means of delivery; 5. Use face to face meetings, email, and conference calls to work together; 6. Plan to evaluate achievements including the process, the impact, and the perception.

	4. Challenge/ Opportunity: Funding
Preferred Future	1. Charity contributions to CTS increased by 50%, at $1M. 2. Private contributions to research have increased by 50%.
Key Result Areas	1. Increase funding applications; 2. Attain funding directly proportional to the total number of CIHR applications; 3. Funding success;
Recommendations	1. Encourage Mentorship and Training: a. Offer grant writing education workshops; b. Develop a robust clinical and basic science mentorship program, ex: CRCRC; 2. Establish a clinical research training program; 3. Increase funding: c. Increase the number of funding applications to CIHR; d. Respiratory researchers exploit CIHR funding opportunities; apply more as a community.

	5. Challenge/ Opportunity: Training and Mentorship
Preferred Future	1. Enhanced recruitment training and support of young investigators in respiratory research.
Key Result Areas	1. Increased recruitment; 2. Support of pre-faculty; 3. Support of new faculty.
Recommendations	1. CTS targeted recruitment "event" for new respiratory fellows; basic and clinical to entice new recruits; 2. Encourage CIHR/CTS/ host institution clinician and basic scientist paired fellowship "buddy" fellowships to promote research at clinical interface; 3. Develop a NIH K29-style new investigator salary award and operating grant separate to the standard CIHR operating grant competition;

Appendix A: Planning Meeting Agenda

National Respiratory Research Agenda
The Fort Garry – La Verendrye Room
November 27, 2009

7:30 am	Arrival and Breakfast	
8:00 am	Welcome……	Denis O'Donnell
8:05 am (Facilitator)	Introduction to the Day ……	David Reid
8:25 am	Review of the Goals of the Meeting ……	Denis O'Donnell
8:45 am	Presentation: The Current State First Speaker: Dr. Jessica Evans, Epidemiologist, Public Health Agency of Canada, *Burden of Respiratory Diseases in Canada* Second Speaker: Dr. Peter Liu, CIHR – Scientific Director, Institute of Circulatory and Respiratory Health, *Federal Research Funding and Opportunities* Third Speaker: Anne Van Dam, Director, Research, The Lung Association *Research Programs and Funding Overview*	
9:45 am	Morning Break	
10:00 am	Presentation: The British Experience ……	Prof. S. Holgate
11:00 am	Presentation: Partnerships – The Essentials ……...	Prof. A.Naimark
11:30 am like?	Development of a Successful Respiratory Research Agenda: What it could look	
12:30 pm	Lunch	
1:00 pm	Development of a Successful Respiratory Research Agenda: Action Plan	
2:30 pm	Afternoon Break	
2:45 pm	Plenary Discussion	
3:45 pm	Key Messages	
3:55 pm	Road Map to Success – Next Steps and Timelines……..	Denis O'Donnell
4:00 pm	Adjourn	

Appendix B: List of Participants

Participants attending the CTS/CLA research meeting November 27, 2009 in Winnipeg PARTICIPATION LIST		
	Names	**Organization**
1	Heather Borquez	Canadian Lung Association, President and CEO Chair, National Lung Health Framework Steering Committee
2	Peter Liu	CIHR – ICRH, Scientific Director, Steering Committee Member, National Lung Health Framework
3	Ilana Gombos	CIHR – ICRH, Assistant Director
4	Jane Wallingford	CLA Board Member, Chair National Research Committee
5	Ainsley Chapman	Director, National Lung Health Framework
6	Irvin Mayers	University of Alberta, Division Director, Adult
7	Hans Pasterkamp	University of Manitoba, Division Director, Pediatric
8	Felix Ratjen	SickKids, Division Director, Pediatric
9	Redwan Moqbel	University of Manitoba, Professor & Head Department of Immunology
10	Brian Graham	Saskatchewan Lung Association, CEO
11	Geoffrey Payne	University of Northern BC, Chair, Basic Science Panel, NGR
12	Diana Royce	AllerGen, Network Centre of Excellence
13	Eric Rousseau	Réseau en santé respiratoire, Sherbrooke University
14	Qutayba Hamid	Meakins-Christie Laboratories, ICRH IAB Member
15	Denis O'Donnell	Queens University, CTS President
16	Andrew Halayko	University of Manitoba, CTS Research Co-Chair Canada Research Chair, Airway Cell and Molecular Biology - Asthma
17	Richard Leigh	University of Calgary, CTS Research member
18	Donna Goodridge	University of Saskatchewan, CRHP Research Chair
19	Shawn Aaron	Ottawa Health Research Institute, CTS Research Co-Chair
20	Smita Pakhale	University of Ottawa, Young Investigator
21	Larry Lands	McGill University, CTS Research Committee Member
22	Stephen Holgate	University of Southampton, British Thoracic Society
23	Richard Kinkead	Laval University Canada Research Chair, Respiratory Neurobiology
24	David Proud	University of Calgary Canada Research Chair, Inflammatory Airway Diseases – Asthma and COPD
25	Martin Post	SickKids Canada Research Chair, Fetal, Neonatal and Maternal Health
26	Brian Rowe	University of Alberta Canada Research Chair, Emergency Airway Diseases
27	Darryl Knight	University of British Columbia Canada Research Chair, Airway Disease - Asthma
28	Janet Sutherland	Director, CTS
29	Anne Van Dam	Director, Research & KT/Canadian Lung Association
30	Michelle McEvoy	Manager, CLA Research Programs
31	George Habib	Ontario Lung Association, CEO

32	Tony Hudson	Alberta Lung Association, CEO
33	Richard Horner	University of Toronto Canada Research Chair, Sleep and Respiratory Neurobiology
34	Lisa Cameron	University of Alberta, CTS Research Committee Member
35	Brandi Walker	University of Calgary, Clinician-Scientist
36	Tillie-Louise Hackett	University of British Columbia, Young Investigator
37	Cory Yamashita	University of Western Ontario, Clinician-Scientist
38	Jessica Evans	Public Health Agency of Canada, Epidemiologist, Chronic Diseases
39	Ynuk Bosse	University of British Columbia, Young Investigator
40	Mark Larche	McMaster University, Canada Research Chair, Allergy and Immune Tolerance
41	Helen Neighbour	McMaster University, Assistant Professor

42	Paramaswan Nair	McMaster University Canada Research Chair, Airway Inflammometry
43	Kent Hayglass	University of Manitoba Director, CIHR National Training Program in Allergy and Asthma
44	Shyamala Dakshinamurti	University of Manitoba, Clinician-Scientist
45	James G. Martin	McGill University, Chair, CIHR Respiratory Systems Peer Review Committee
46	Mark Inman	McMaster University, Associate Professor
47	Curt Smith	Manitoba Lung Association/CLA Vice-Chair
48	Margaret Bernhardt-Lowdon	Manitoba Lung Association, CEO
49	Jean Bourbeau	McGill University, CTS Research Committee Member
50	Louise Giles	University of Manitoba, Steering Committee Member, National Lung Health Framework
51	Arnold Naimark	University of Manitoba, Dean Emeritus of Medicine
52	Newman Stephens	University of Manitoba, Professor, Physiology
53	David Reid	Intersol Group, Facilitator
54	Susan Dinan	Intersol Group, Recorder

Appendix C: Expectations

Participant Expectations
• To develop funding sources other than CHIR to increase research priority and partnering with industry; • Increase respiratory research profile at CIHR; • Explore how the Lung Health Framework can be utilized to advance funding for research; • To extend the cadre of young clinical respiratory mandate an extra year; ask Royal College to extend young clinician – 1 extra year for the respiratory program. • Expansion of partnerships with CLA and CTS; • Get a firm commitment that to follow-up on actions decided today and assess the likelihood that we will be successful; • Empowering national lung community to exploit funding; • Making research saleable but more appropriate sexy; • Look at where the funding is and how to increase our share; • Increase funding for basic research; • To identify the possible barriers from the past so we can move forward with a better plan; to what using a set of strategies to increase the profile; • To raise awareness of the importance of respiratory research to the public and to the main funding agencies; • Better organize the community; • Assess likelihood that we will make a difference; • Get commitment to follow through; • Get young clinical trainees involved in research and leading to clinical investigators; • Identify ways to increase the research profile and recognize the international role that research provides; • Develop a concrete set of priorities and an action plan for funding; • Bring the clinical scientist back into the research community in Canada; • Understand/ improve inclusiveness with all stakeholders; • Plan t o move forward, set of strategies to increase profile, increase research potential and funding; • Finding out where research has been/ mistakes made and what has worked; consider barriers to research; • Develop a transitional Pier I to Pier IV network for respiratory disease; • Funding for respiratory disease.

Appendix D: The Current State, Panel Questions and Answers

- *Question for Dr. Liu: Concerning the lack of funding for mid-level and senior investigators, how do you encourage people to maintain a scientist career?*
  Response: This is not a CIHR decision, it is an elected mandate. There are three strategies suggested to mid and senior investigators: 1. CRSC is a political process so it is important to work with the chairs and the institution to make sure that research is a priority, 2. work with partners to develop chairs for senior investigators; It is a conundrum, have been working with the IAB sub-committee to find solutions; would appreciate recommendations from this group.

- *Question for Dr. Liu: Do "we" think that the current level of funding is adequate given the burden of respiratory disease?*
  Footnote: The diabetes figure is not correct in the presentation (data will be corrected).
  Response: It is true that respiratory community has been languishing in terms of CHIR dollars and we would like to see it increase its amount. There are opportunities and it is important to have a competent and innovative community and the money will follow.

- *Question for Anne Van Dam: You mentioned that $500,000 was dedicated to research, how is value determined and what strategies can be used to access it?*
  Response: The direction came to CLA board and research assessments received: try to leverage some of funding with partnership and with corporate sponsorships. The national and provincial contributions are about 2 million all tolled. On the provincial side, we have not done a good job on marketing the need for research. We need to develop a strategy for research and market the need for more research. Getting the message out is important.

- *Question for Dr. Liu: How does CIHR plan to match research funding to the burden of disease?*
  Response: We put it in the strategic priorities and at the end of the day. The funding is never in proportion to the burden of disease, ex: HIV Aids and Breast Cancer. Much of the focus has to do with the energy of the community.

- *Question for Dr. Liu: Why doesn't lung disease have a higher public profile?*
  Response: We take a neutral position (can't lobby government), however we can take the case and present the strategy; informed by recommendations. We can get the message to the public where appropriate. Decisions are never based on statistics – they are emotionally based. Having a champion profiling the cause is very powerful.

- *Question for Dr. Liu: Who makes the decision on research priorities and what criteria are used?*
  Response: There is a strategic planning process. The first source of information comes from the community. The advisory board gets input from the research community, they look closely at capacity – the ability to deliver is matched to the research capacity. There is a need to look at the dollars spent compared to the potential impact in terms of scientific excellence.

- *Question for Dr. Evans: Is there anything in your agency where you are making a better link to the research going on in the surveillance program?*
  Response: We are working to expanding data sources to include not just self-reported data- by using provincial data and information from the community to expanding our sources. We have specific member from the community participating in these groups.
  Comment: what I would like to see is that these partnerships build on existing research and also define what is needed in the future.
- *Question for all: There is concern for the general lack of appetite for research and the perceptions attached to this attitude. What do we need to do in order to address this situation?*
  Response: This lack of appetite is not unique to respiratory research. It is important to identify trainees early. Equally important is to have leadership commitment and culture that transmits passion and persistence to the trainees thereby increasing their chances of becoming successful researchers / investigators.

Appendix E: The British Experience, Questions and Answers

- *Question: How do we get support for the lung health research?*
  Response: Industry is international now, if you are doing good work, industry will come to you to support. There are some very influential people here in the industry… did not have difficulty mustering them for their meeting so there is no lack of willingness to support.

- *Question: How is the distribution of funds decided? Individual versus Investigator driven? How are the priorities set?*
  Response: Investigators work from the heart and not be constrained. Pure scientists need to be protected. A consortium can mount grant proposals based on scientist interest. Spot young clinicians early in the university level before they reach PHD. Have academic clinical fellowship – take people in their junior years fro training, give them initial amounts to encourage them to continue in research, i.e.: academic clinical fellowship scheme.

- *Question: What are the pros and cons of having centers versus virtual sectors?*
  Response: There is room for network and centres; they are analogous to hub and spokes because both serve an important function. In the competitive arena on the international level, you cannot be spread all over the place. You need to make a decision to concentrate your efforts in the area where you perform well. Ex: Holland priorities exercise: universities successfully competed together. This has happened all over because government will not support research; by creating imperative in the university sector through a research assessment exercise, rated for the research output, makes universities concentrate their efforts on what they do well.

- *Question: We have a unique opportunity already forged link with PHAC. How do we take advantage of this relationship in order to move forward?*
  Response: What you will decide this afternoon – set up a table with individual representatives, this is the 4-5 things you will do in order to move forward. There seems to be tremendous consensus. Problem is lack of confidence because of constant failure. Shift focus to growth rather than deficit.

- *Question: We recognize that research is not advantaged. How can we promote and nurture research?*
  Response: It is very important to change the mindset / concept that people don't want to do research. People are very interested in research. When people experience top class people who empower them to move forward. They move forward, there is international competition. Empowers them to apply for funds they may not normally apply for. Get the buzz to get younger researchers interested.

- *Question: Can we come up with our own collaboration, develop our own report and then get government to buy*
  Response: You need to get the public on board – public lobby the PM and ministers to get the focus. Getting a report with priorities including multiple agencies, speaking with a single voice – will have a powerful impact.

- *Question: What are the pitfalls to be avoided?*
  Response: "Taking your foot off the accelerator" would be a pitfall. Once actions are taken and the momentum builds, it is important to sustain and maintain the effort, to nurture the youth to keep the momentum moving forward.

- *Question: How did you bridge the dichotomy between basic and clinical research communities?*
  Response: The population of health sciences (academeology) informs government about the funding decisions. We look at smaller studies and extrapolate back to the larger population. The clinical sciences being explored are to embed studies in large, well defined populations. Amazing that we are living in respiratory medicine, we have not had collection where we embed science in the public health agenda. Connections need to be made.

- *Question: How did you, as a new structure, influence the charities to re-examine themselves and their structures? Response:* Charities are bodies that the public support; their structures are different from government organizations. They are interested in the patient's improvement, and at moment charities are the only interface with the public. You can offer to help them with their peer review process as it is your strength. Charities can use patient base effectively to prioritize lung heath issues.