



# 20 Questions with... Bartha Knoppers

Professor, Centre of Genomics and Policy, McGill University

## *20 Questions with 20 Stem Cell Scientists from Across Canada*

### 1. Where were you born? Where did you grow up?

I was born in Hilversum, which is just outside of Amsterdam, in the Netherlands. I was the fourth of six children.

My family and I actually came over to North America on one of those big boats as immigrants in 1955. Even though I was a child, I remember the boat, because I had my birthday on the boat. Dutch people do big things for birthdays, and I remember the size of the cake – it seemed so big, but then I was so small!

I remember the boat and I remember landing in New York. We had some family there and then we all flew to Edmonton, Alberta.

My father was a Minister and he had been called by the church to be a minister in Edmonton. We lived on the outskirts of Edmonton in an area called Beverly. Some of the roads were not yet paved and the sidewalks were still missing. But the people had built the church there themselves as well as a school and the parsonage to go along with it. The area we lived in had many immigrants from all over – the Netherlands, as well as people from Ukraine, Germany, Ireland and many other countries.

We were six kids in my family and we all lived in the parsonage and attended the school. It was quite an experience, growing up in Alberta, surrounded by immigrants, learning to survive the Alberta winters. For the first five years, we were so integrated into the church and its community, we did not really get to know anyone who was a 'real' Canadian.

But that marginality did not really hit home as much until five years later when my father was called to another church. Our whole family picked up and move to Montreal, Quebec. This time we were all put into a Canadian school. While it was a public school, we were all required to wear uniforms. It was meant to be equalizing, but it was still quite obvious who came from somewhere or had 'less' from our shoes and coats, and who was not really English speaking as their first language.

When I got to high school, things changed for me. I was enrolled in an enriched level program. I became so excited about learning – whether it was biology, which I hated, or history, which I love. We had a professor who treated the Communist Manifesto like his bible. I was finally intellectually challenged, and in that class, everyone was there to learn. That was an equalizer. It was less about class or origin and that marginality was replaced by shared intellectual excitement.

As an example, I sat by a fellow classmate named Jack Szostak. He was an immigrant too. We learned together, wrote poems together. He later went on to win a Nobel Prize. It was just an exciting time, where everyone was there to learn



*Bartha in the early years*

and no one cared about accents or funny last names – it was a very positive environment. Once you get excited about ideas and questioning everything and at the same time having fun, then you feel safe and accepted.

That is something I now strive to create for my students and research associates.

## 2. Where did you go to school?

After high school I went to Calvin College in the United States. I got into a bit of trouble there, protesting the Vietnam War. I was into theatre and literature – I had no interest in law at that time.

I eventually ran out of money, even though I was taking on part time jobs, like waitressing and learned more about human nature in that job. I ended up returning to Canada and finished my BA at McMaster University in Hamilton, Ontario.

I then went back to Edmonton and did my Master's at the University of Alberta, in Comparative Literature. I started working on my doctorate, focusing on Caribbean and Quebec poetry. I was looking at how colonization affected how different cultures expressed themselves over time as they went from being colonized to becoming independent and created their authentic literature.

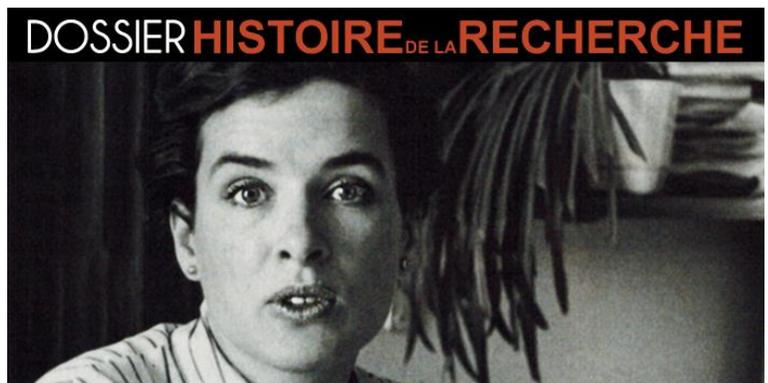
Unfortunately, my PhD advisor got into some trouble and there was no one at the university who had expertise in third world literature, as it was called at the time, who could replace him.

The university left it to me to find myself another professor and there really wasn't anyone in Edmonton, Alberta.

So I thought, 'oh well, I don't want to be a professor anyway. I am going to go into law and change the world.' So, I did another seven years of university, starting at McGill in 1976, then in Paris at the Sorbonne followed by the UK at the University of Cambridge. I finally graduated with a doctorate in comparative medical law, two babies and passed the Bar in 1985.

I really believe you can never spend too much time at university. I am glad I did literature first because it's everything – it's history, it's art, it's politics, it's culture. And now I like to write. A lot of scientists don't like to or struggle with writing. But with my training in literature, combined with my legal training it is a great background.

I always tell people to do everything before they become a practising lawyer because you are going to be dealing with humans and the more you can understand and appreciate the complexity of dealing with humans the better lawyer you will be.



*Bartha making her mark in academia*

## 3. What did you want to be when you grew up?

When I was a little girl, I wanted to be a ballet dancer. I danced all the way through, and into high school in both classical and more experimental dance. I also learned to play the viola. It was all very good training, but I am just not gifted and at a certain point you just have to move on.

#### 4. What are you working on right now?

I am mainly working on data governance models for large international collaborative projects, so they are able to share data in a responsible way and yet exploit the full scientific value in a way that respects the original 'gift' of the person who gives their samples or data for scientific purposes.

I really think that we are much too frightened of legal consequences and too conservative in a way that our protectionism of patient privacy might not be at all what they might really want. They might really want to be able to contribute more, provided it's done responsibly in a secure way. I think that the open science, and the more international use and sharing of data makes up about 80 per cent of my current research.



*At a P3G (Public Population Project in Genomics and Society) event in 2017*

#### 5. What attracted you to stem cells?

My doctorate was on reproductive technologies. I actually met Steptoe and Edwards (who developed the in vitro fertilization procedure for treating human infertility) at Cambridge while I was studying there.

So, I had always been working in the areas of embryo research, prenatal diagnosis, abortion law, contraception law, particularly in developing countries, and looking at all the different constraints or possibilities for research involving human reproduction.

I had heard of Janet Rossant of course, although she was working more in mice at that time. I had no formal scientific training but by attending scientific conferences across Canada, where I often understood only about one third of anything, I sort of picked up on the vibe of stem cells. I began to understand how they were contributing to understanding of human health and disease, and the possibility that they were closer to therapies. With that more potential for therapies than simply doing, preimplantation diagnosis or prenatal genetic diagnosis, where you are dealing more with the consequences than you are with trying to build the treatments.

#### 6. Who in your opinion, are the top three Canadian stem cell researchers in history?

Well, there is Janet Rossant, whom I have already mentioned.

I also admire Derek van der Kooy. I worked with him on some cutting-edge international committees around chimeras and developing safe and ethical research methods here in Canada.

And the one that invited me in and got me involved the most, was of course a key founder of the Stem Cell Network, Ron Worton. Ron invited me to an international meeting in Japan back in 1990 and I really got to know him through his work with muscular dystrophy. He allowed me to meet patients and get involved with patient organizations and an international genetic alliance. He was a model for me.

## 7. What are your predictions for stem cell advances in the next 5, 10, 20 years?

Well, there is a new development happening right now which could be very monumental. Apparently, some scientists are arguing for the 14-day embryo rule to be dropped.

The 14-day rule sort of gained worldwide recognition both as policy and as law in many countries after the [Warnock Committee](#) ruling in 1984 which imposed the 14-day limit for how long a human embryo may be kept once fertilized.

What are we going to do? Will we extend this time limit in order to understand embryo development and human health beyond the 14-day rule? This will be an interesting ethical, legal and social exercise.

Another emerging issue is covered in a recent paper in *Nature* about the modeling of human blastocysts by reprogramming fibroblasts into iBlastoids. In other words, the issue and activity of reprogramming cells. Changing the cells from their original purpose or function, into a new purpose or function – eventually recreating models for research.

So potentially, the sources for stem cells are going to change, and the purposes for which they are used. We are already creating stem cell therapies, all targeted by genomics, what I call cellular genomics. And this is all only in the somatic (or adult) stem cells – person by person, rare disease by rare disease – a model which is already very limited to the present, and carefully circumscribed.



*Accepting the 2019 Henry G. Friesen International Prize in Health Research*

If one day we were to move to a clinical applications route of research in Canada, of germline therapies affecting future generations, that would be the next ultimate ethical challenge.

I was on the International Commission that just finished its report in 2020 on the potential clinical applications for human germline editing. We didn't approve it. But if it were one day to be possible, we laid out the responsible steps. Many questions remain to be resolved around what the conditions for that would be.

So, I am excited about what the future holds.

## 8. What would you describe as the most significant moment in your own research career?

It is hard to choose a single moment.

If I had to choose my proudest personal moment, it would be when I became an officer of the Order of Canada. My parents were there, and it was really a big deal for them and my family.

## 9. What are you reading right now?

I am currently doing a book review for a magazine on the book *The Code Breaker*, by Walter Isaacson. It is a book about Jennifer Doudna, the Nobel Prize Winner for CRISPR and her mentor. Her first mentor and doctoral advisor at Harvard was Jack Szostak – the very same Jack Szostak who sat beside me in high school in Montreal!

I am also reading a novel about the plague, partly because it fits so well into my current work with the COVID-19 Vaccine Task Force. Based in England in 1665 during an outbreak of the bubonic plague, the book is called, *Year of Wonders*, by Geraldine Brooks. It is depressing but so beautifully written. And it is interesting to read it at this time – as we are in

lockdown and experiencing the curfew and everything else. We are living in somewhat of a parallel world now in 2021 with a modern plague. It was mesmerizing and quite instructive.

## 10. Who is your favourite scientist?

I would say [Charles Auffray](#), the President and Founding Director of the European Institute for Systems Biology and Medicine. He is a true data visionary.

## 11. What in your opinion is the single most important health science or biomedical breakthrough?

RNA-based vaccines. Not just because of what we are currently living through, but because of their immense international impact on the population. In my opinion, the impact of vaccines is greater than any other discovery, therapy or drug because it is not just the sheer numbers that are affected but because they are usually created to treat conditions, diseases or viruses that come from a combination of nature, the environment, and both animals and human species. The challenges vaccines address are complex and they strike all levels of society – obviously with some populations more at risk than others because of lack of access to medical care.

So, for impact on humanity, vaccines are at the top.



*Touring with the National Institute of Genomic Medicine (INMEGEN) in Mexico*

## 12. What is your favourite place to visit? Why?

My favourite place in the world is Hong Kong. It has everything. It is artistic, quixotic, multicultural, beautiful. It is modern and yet you still see things there sometimes that seem like they have not changed since Marco Polo. There are parts, when you get a little bit away from the city centre, that look like history has just stopped, or never started. It is this great combination of very old and ultramodern. It is a financial hub, so most people understand English, but you can still find pockets where you find yourself using sign language to communicate. It is just such a vibrant city – I love it. Would I live there – while I am adventurous, I am not sure I would subject my family to that. Particularly not under this current regime.

## 13. It is your night to cook – what is your go-to meal?

Being Dutch, I am a huge fan of Indonesian cuisine. The meal I love to make for my family is Nasi Goreng. It is made with Indonesian spices, rice and pork. You have these crackers that you cook with oil and there are lots of vegetables. And it is topped off with crushed peanuts. I love it, and it is great because you can make huge batches when you have a group of people over for a meal.

## 14. If not a scientist, what would be your dream job?

If it wasn't so slow, it would probably be working with UNESCO. To work among all those cultures, and languages – especially in the education and science domains. There is just so much promise there.

### 15. What is the best piece of advice you have ever been given? What advice would you give to a trainee just starting out?

I think it was from my parents. They definitely gave me a lot of free rein in my life to try new things. But they said to me once, 'don't do anything that is boring.'

I mean, I did work as a waitress and in bookstores, but it was a means to an end, so I could afford to work my way through school. But neither of these were boring because I was always in contact with human beings – even when in restaurants they could be quite mean. And really, in bookstores, most of that was wonderful – what more can you ask for if you have books?

But if I had to find a job, I would really do anything that was necessary in order to survive. As long as the job wasn't boring.

My advice to someone just starting out? Learn everything.

### 16. What is something you think everyone should do at least once in their lives?

I like to race cars. I like to go to the track and drive fast cars – the last one I drove was a Ferrari. My daughter gave that experience to me as a birthday gift and I was the only woman out on the track. I have no fear of speed!

I know it is not for everyone. I know some like to bungee jump, jump out of a plane, climb a mountain. But really, just find something that you have always dreamed of doing, even if it is on a smaller scale (than racing cars) and dare to do it.



*Speaking at the European Commission*

### 17. What skill would you most like to master?

I took four years of Latin (ugh)! But I really wish I had learned to type.

### 18. What is your favourite movie?

This is so kitsch, but honestly, it is *The Sound of Music*. I watch it once a year. It is a classic.

And did you know, Christopher Plummer, who played the father in the film, hated the movie. He hated it until he was about 70 years old. He was at some family function and there were a lot of kids there. They were watching the film and he wandered in and stood there watching them the movie. He watched their eyes light up and their expressions on their faces and saw how they were enthralled by the beauty of it. It had this kind of magic, and how these kids could sing all these songs and he saw it through their eyes. He changed his mind about the movie because he realized that it had this magic in it – but he only discovered that once he saw it through the eyes of children.

### 19. Who is your favourite Canadian?

I have a lot of respect for our local MP, the Hon. Marc Garneau. He is a former astronaut, turned politician and now he is a minister. Politics can be an awful, tough life. I admire the dedication, the simplicity, and the honesty he brings to it.

You get what you see with him. He is a lovely person. He has no guile, and he is not in it for the self-aggrandizement. I have to admire his public service. To have an astronaut, who goes out into space and the universe and then comes back to serve, in a very humble, intelligent way is very impressive for me. It is about real public service and I really respect that.

## 20. What do you wish you knew more about?

Everything. I was brought up when girls were put into domestic, not industrial, classes. So, I can sew, embroider, or make covers for furniture but I would have liked to make furniture, fix cars, etc. I wish I had more understanding of practical things, like electricity.

And I wish I knew more about history.

