Vulnerable populations and genetic disorders: a socio-science approach to the application of genetic technology in China
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In August 2004, I came to the Netherlands for an interview for the position of PhD candidate. That interview brought me a wonderful chance to attend an international research project, the Socio-genetic Marginalization in Asia Programme (SMAP), and an opportunity to do research work in Amsterdam University from 2005. This was just like opening a door for me into the social-genomic research field. Such a research field is an interdisciplinary frontier research area. From a social science perspective, to understand the social implications of genetic testing is very attractive and challenging for me. And using English as working language, and writing academic papers in English, is also a big challenge. I had put in a lot of hard work for my research. In fact, as time has passed, I have loved my work more and more, and feel my research more and more meaningful. I have gradually come to understand the application of genetic testing in China, and the difficulties faced by families affected by genetic disorder in Chinese socio-ecoFonomic, culture and political contexts. During my research, I interviewed many families. I appreciated it greatly that my interviewees shared their sad stories with me, revealing to me their sorrows and bringing out grievances that lay buried deep in their heart. I know it is beyond my power to change their situations. However, my understanding and kind consolation might relieve some of their psychological pain. And I also feel gratified that my research has contributed to a better understanding of the social and ethical issues in regard to the application of genetic testing and to the situation of the vulnerable population.

The last four years have been hard but very valuable for me. Now, when I look back on it, I feel it is more precious. During this period I made progress inch by inch. I published several academic papers in international journals and gave presentations at international conferences. I know that I could not have reached such achievement without support and help from the people
around me. Here, I would like to express my earnest appreciation to my supervisors, Doctor Margaret Sleeboom-Faulkner and Professor Anita Hardon. Margaret is also SMAP Programme director. My supervisors have evaluated my research work progress on every stage, provided me with valuable advice on my study and comments on paper writing. They have been extremely helpful in their comments. Whenever I have been stuck and needed instruction, I have always received quick feedback and comments from them. And also, when I felt depressed, they encouraged me in a timely way and gave me confidence. I feel so lucky to have them as my supervisors. This is especially true of Margaret Sleeboom-Faulkner, who gave me very valuable advice on the research framework, design and thesis writing. For all of my articles, she gave instructive direction and many very valuable and constructive comments. My articles reflect her hard work and assistance. I owe much of my progress and achievement to her strong and helpful support. There is no words can fully express my appreciation.

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Finally, I would like to point out that any mistakes and shortcomings in this thesis are my own responsibility.