In March 2012, at the initiation of this thesis, DIPG research was mostly regionally organized, small-scaled, and geographically scattered. More importantly, in the Netherlands, no prospective DIPG-specific clinical trial had yet been conducted. Thanks to the financial support of the Semmy Foundation (Stichting Semmy), the opportunity was provided to initiate the first single- and multi-center trials. The studies that were initiated at VU University Medical Center cover all aspects of DIPG, ranging from clinical symptoms, diagnostics and treatment strategies, to pre-clinical laboratory research on tumor material obtained via autopsy. In Part I of this thesis, the results of these studies are presented in analogy to the disease course of DIPG, from time of diagnosis to death.

Since DIPG is so rare, there was not sufficient data to provide all answers to the many research questions raised. Therefore, in Part II of this thesis, the perspective of the research was expanded to a larger scope, both in time and scale. Starting with historical cohort studies and extensive literature reviews to learn from the past, we reached out to our colleagues at national, European and global level. Important subjects such as alternative treatment strategies, survival prediction, palliative care and use of steroids in DIPG patients were investigated.

Finally, in Part III, we put into practice what we had learned, which is that regional, small-scaled, and scattered research initiatives are not efficient in a global aim to unravel and cure this rare disease. This part of the thesis describes the establishment of an international research infrastructure, formed by a collaboration of biomedical experts within the SIOPE DIPG Network, and the development and initiation of the SIOPE DIPG Registry and Imaging Repository, in parallel to the International DIPG Registry. These efforts have resulted in the first worldwide initiatives to increase DIPG patient data and improve the integration, speed, quality, and coherence of research into DIPG. For the first time, large datasets have become available for robust analysis of clinical, radiological and biological disease characteristics, as well as treatment strategies.