

3. パーキンソン病関連

- 1) 臨床：# 1、#39-43
- 2) 遺伝子：#27-28
- 3) 生化学、分子生物学：#30-33
- 4) 治療：#34-38

4. 進行性核上性麻痺・大脳皮質基底核変性症

- 1) 遺伝子：#22
- 2) 病理：#23
- 3) 臨床と画像：#24-25、#44

5. その他

- 1) 遺伝性ジストニア・パーキンソニズム (DYT3)：#29
- 2) 多系統萎縮症：#45
- 3) プレセニリン1 遺伝子変異による家族性レビー小体型痴呆・アルツハイマー病：#46
- 4) 下オリーブ核変性：#47

<個別研究課題>

内容は本報告書の「研究発表」の項目に掲載

1. 葛原茂樹：ALSデータベース研究第2報：基礎集計結果
2. 湯浅龍彦：ALSの死因に関する2004年アンケート調査結果
—湯浅班ALSの死因に関する調査研究グループからの報告—
3. 近藤智善：筋萎縮性側索硬化症の発症関連要因に関する疫学的検討—第1報—
4. 葛原茂樹：紀伊半島の筋萎縮性側索硬化症/パーキンソン痴呆複合に出現するPigmentary retinopathy
5. 葛原茂樹：familial frontotemporal dementia with motor neuron diseaseの1家系
6. 中島健二：家族性筋萎縮性側索硬化症 (Leu126delTT) モデルマウスの作製・解析
7. 祖父江元：変異SOD1-トランスジェニック (Tg) マウスにおけるSOD1凝集
—特にDorfinとの関連について—
8. 青木正志：ALSラットモデル脊髄におけるグリア系前駆細胞の増殖
9. 郭 伸：カイニン酸持続髄注によるALS病態モデル動物の開発
10. 祖父江元：筋萎縮性側索硬化症における運動ニューロン特異的遺伝子発現プロファイル
11. 森若文雄：プロテアソーム障害による運動ニューロン変性
12. 吉良潤一：運動ニューロン疾患患者髄液サイトカイン/ケモカインのfluorescent bead-based immunoassay法を用いた多項目同時測定による解析
13. 岡本幸市：筋萎縮性側索硬化症におけるネスチンの発現に関する免疫組織学的検討
—Creutzfeldt-Jakob病との対比を中心に—
14. 阿部康二：ALSモデルマウスへのIGF-1治療におけるIGF-1RおよびIRS-1の変化
15. 水澤英洋：siRNA過剰発現によるSOD1ノックダウンマウスを用いた筋萎縮性側索硬化症の遺伝子治療
16. 岩崎泰雄：Wobbler mouse に対する緑茶療法：カテキン，テアニン，カフェイン投与との比較
17. 梶 龍兒：筋萎縮性側索硬化症に対するメチルパラミン大量投与の長期効果—第3報

18. 荒崎圭介：運動単位推定数 (MUNE) 自動算出のためのプログラム開発
19. 林 秀明：遠心系以外のALS病変の意味付けについて
20. 貫名信行：ハンチントン病モデルマウスにおけるナトリウムチャンネル β 4サブユニットの発現低下
21. 長谷川一子：UHDRSの問題点
22. 高野弘基：進行性核上麻痺とタウ遺伝子領域の関連
23. 高橋 均：Astrocytic plaques と tufted astrocytes の共存、および高度の大脳白質変を呈した前頭側頭葉痴呆の2剖検例：その分類上の位置づけ
24. 近藤智善：すくみ足症例の病態生理学的検討
—進行性核上性麻痺，純粋無動症の脳血流SPECT—
25. 湯浅龍彦：PSP画像所見の再検討
26. 川井 充：神経変性疾患における効用値QOL測定の妥当性
—第2報 パーキンソン病を対象とした検討—
27. 長谷川一子：相模原パーキンソニズムの原因遺伝子の探索 (6)
28. 戸田達史：多数の候補遺伝子SNPタイピングによる孤発性パーキンソン病の関連解析
29. 梶 龍兒：伴性劣勢ジストニア・パーキンソニズム (DYT3) の遺伝子と病理
30. 阿部康二：パーキンソン病患者のレビー小体におけるPael-R, Parkin およびGlupの関与
31. 森若文雄：パーキンソン病におけるmacrophage migration inhibitory factor (MIF)の解析
32. 下濱 俊：プロテアソームとドーパミンニューロン死
33. 中島健二：L-ドーパ/ドーパミンは細胞内凝集体形成を促進する
34. 水野美邦：パーキンソン遺伝子によるパーキンソン病モデルの遺伝子治療
35. 野元正弘：パーキンソン病患者においてドンペリドン併用がL-dopaの血中動態に与える作用
36. 野元正弘：パーキンソン病患者においてグレープフルーツジュース併用がカベルゴリン血中濃度に及ぼす影響
37. 中野今治：パーキンソン病モデルサルへのES細胞由来神経幹細胞の移植
38. 橋本隆男：パーキンソン病のジスキネジアに対する定位脳手術効果と問題点
39. 久野貞子：パーキンソン病における睡眠障害
40. 久野貞子：パーキンソン病における幻覚の分類と出現機序
41. 加知輝彦：パーキンソン病における視覚認知機能—第2報—
42. 吉良潤一：大脳基底核運動回路と小脳—大脳運動回路のネットワーク解析
43. 内藤 寛：cyclogram によるすくみ足の検討
44. 根来 清：大脳皮質基底核変性症と進行性核上性麻痺はルーチンMRIで鑑別できるか
—中脳・第三脳室に注目して—
45. 中川正法：拡散テンソルによる多系統萎縮症脳解析
46. 高橋 均：プレセニン1 遺伝子変異によりレビー小体型痴呆と変異型アルツハイマー病の病理所見を呈した1家系
47. 水谷智彦：下オリブ核変性についての病理学的研究

IV. その他の活動

- 1) 平成16年度厚生労働科学研究費補助金（難治性疾患克服研究事業）事後評価用資料の提出（平成17年1月6日）

本研究班の3年間の活動と代表的成果を厚生労働省に報告した（別に発行の2002年度～2004年度 総合研究報告書参照）。これは、成果評価委員会の資料となるものである。

- 2) 「特定疾患治療研究事業」及び「難治性疾患克服研究」の事業評価と疾患克服に向けた今後の研究の展開について（平成17年2月4日）

本研究班の前身の「筋萎縮性側索硬化症調査研究班」と「パーキンソン病調査研究班」の時代から今日までの、担当8疾患について、研究成果等の報告を、厚生労働省に行った。（別に発行の2002年度～2004年度 総合研究報告書参照）

- 3) 特定疾患治療研究事業における軽快者基準導入に係る検討について（平成17年2月10日）

特定疾患の改善基準について、担当8疾患について、厚生労働省に報告した（巻末に資料として綴じ込み）。

- 4) 「パーキンソン病と関連疾患（進行性核上性麻痺、大脳皮質基底核変性症）の療養の手引き」発行（平成17年3月10日）

班員が担当して、疾患、治療、療養、研究に関する解説書を発行し、患者団体、都道府県の難病支援センター・難病ネットワーク研究会・難病専門員、班員に配布した。「分かりやすく、簡明に」をモットーに、Q&A形式で執筆した。各界の意見を参考にして、今後ALS、ハンチントン病に関しても作成することを検討している。（表紙・目次を巻末に資料として綴じ込み）

- 5) 難治性疾患克服研究推進事業研究成果発表会（平成17年3月15日）

東京・駒場エミナースにおいて実施された、ヒューマンサイエンス振興財団主催の上記発表会において、主任研究者の葛原が神経変性疾患調査研究班を代表し、「パーキンソン病とパーキンソン関連疾患の研究」と題して、疾患の説明と研究班の研究成果、今後の方向について発表した。この会場で、上記の「手引き」を配布した。他に、「炎症性腸疾患」、「筋萎縮性側索硬化症の画期的治療法開発」、「SLE」について発表があった。

- 6) 2002年度～2004年度(平成14年度～平成16年度)総合研究報告書作成（平成17年3月31日）

今期3年間の本研究班の研究成果全般を「総合研究報告書」として作成し、厚生労働省に提出

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