

# aHUS Registry: PUBLICATIONS

Authors	Title	Status	Citation
Licht C, Ardissino G, Ariceta G, Cohen DJ, Cole A, Gasteyger C, Greenbaum LA, Johnson S, Ogawa M, Schaefer F, Vande Walle J, and Frémeaux-Bacchi V	The global aHUS Registry: methodology and initial patient characteristics	Published	BMC Nephrology 2015 16:207
Woodward L, Johnson S, Vande Walle J, Beck J, Gasteyger C, Licht C and Ariceta G	An innovative and collaborative partnership between patients with rare disease and industry-supported registries: the global aHUS registry	Published	OJRD 2016 11:154
Schaefer F, Ardissino G, Ariceta G, Fakhouri F, Scully M, Isabel N, Lommelé Å, Kupelian V, Gasteyger C, Greenbaum LA, Johnson S, Ogawa M, Licht C, Vande Walle J, Frémeaux-Bacchi V	Clinical and genetic predictors of atypical hemolytic uremic syndrome phenotype and outcome	Published	KI 2018 94(2):408

# aHUS Registry : Congress ABSTRACTS

Year	Congress	Authors	Title/Topic	Region
2016	GPN	Pape L, Haas C, Konrad M, Thaiss F, Habbig S, Vester U, Zschiedrich S, Bald M, Billig H, Feldkamp T, Thumfart J, Beckermann J, Faulhaber-Walter R, and Schaefer F	Manifestationen des atypischen hämolytisch-urämischen Syndroms (aHUS) bei Kindern und Erwachsenen: Daten aus dem weltweiten aHUS-Registry	Germany
2016	PAS/ ASPN	Schaefer F, Licht C, Ardissino G, Ariceta G, Kupelian V, Gasteyger C, Greenbaum LA, Ogawa M, Vande Walle J and Frémeaux-Bacchi V	Manifestations of Atypical Hemolytic Uremic Syndrome (aHUS) in Pediatric and Adult Patients Enrolled in the Global aHUS Registry	US
2016	BRS	Johnson S, Licht C, Ardissino G, Ariceta G, Cohen DJ, Gasteyger G, Greenbaum LA, Ogawa M, Kupelian V, Schaefer F, Vande Walle J and Frémeaux-Bacchi V	Atypical Haemolytic Uraemic Syndrome (aHUS) in children and adults: data from the global registry	UK
2016	IPNA	Schaefer F, Ariceta G, Lommelé Å, Kupelian, Licht C and Frémeaux-Bacchi V	Age at onset, renal survival and extrarenal complications in patients with aHUS: Findings of the global atypical haemolytic uraemic syndrome registry	Global
2016	SIN	Cresseri D, Maringhini S, Colussi G, Rigotti A, Giordano M, Gesualdo L, Gasteyger C, Naso A and Ardissino G	Sindrome emolitico uremica atipica (SEUa): dati sui pazienti italiani arruolati nel "Global aHUS Registry", il registro internazionale per pazienti affetti da sindrome emolitico uremica atipica	Italy
2016	DGfN	Haas C, gasteyger C, Ogawa M, Kupelian V, vande Walle J, Hoppe B, Pape L, Vester U, Konrad M, Weber L, Mitchell A and Schaefer F	Manifestations of atypical haemolytic uraemic syndrome (aHUS): German data from the global aHUS Registry	Germany
2016	SFNDT	Loirat C, Schaefer F, Frémeaux-bacchi V, Delmas Y, Deschennes G, Boyer O, Fila M, Presne C, gasteyger C, Fakhouri F and Rondeau E	Caracteristiques des patients inclus en France dans le registre international du syndrome hemolytique et uremique (SHUa)	France

# aHUS Registry : Congress ABSTRACTS

Year	Congress	Authors	Title/Topic	Region
2016	HAA	Isbel N, Hughes P, Abraham A, Kausman J, Lim W, Chapman J, Chadban S, Mantha M, Brown F, Hsu D, Licht C, and Frémeaux-Bacchi V	An Observational, Non-Interventional, Multicentre, Registry Of Patients With Atypical Haemolytic Uraemic Syndrome (aHUS): A Review Of The Baseline Characteristics Of Patients Treated With Eculizumab In The Australian Cohort	Australia
2016	ASN	Schaefer F, Fakhouri F, Kupelian and Licht C	Age at onset, complement abnormality and renal survival in patients with aHUS enrolled in a global registry	Global
2016	ASN	Siedlecki A, Isbel N, Vande Walle J, Kupelian V, and Cohen DJ	Timing of eculizumab treatment and the need for dialysis in patients with aHUS who receive a kidney transplant	Global
2016	ASN	Woodward L, Ariceta G, Gasteyger C, Johnson S, Vande Walle J and Licht C	An innovative collaboration between patients and an industry-supported rare-disease registry	Global
2016	Complement UK	Woodward L, Ariceta G, Gasteyger C, Johnson S, Vande Walle J and Licht C	An innovative collaboration between patients with aHUS, patient organisations and an industry-supported rare-disease registry	UK
2016	ASH	Scully M, Johnson S, Kupelian V and Greenbaum LA	Systemic Involvement at Entry into the Global Atypical Hemolytic Uremic Syndrome (aHUS) Registry	Global
2015	GPN	Hoppe B, Licht C, Ardissino G, Ariceta G, Kupelian V, Gasteyger C, Greenbaum LA, Ogawa M, Vande Walle J and Schaefer F	Das globale aHUS Register: ein erster Überblick über Patienten aus Deutschland und Österreich	Germany
2015	ESPN	Schaefer F, Licht C, Ardissino G, Ariceta G, Kupelian V, Gasteyger C, Greenbaum LA, Ogawa M, Vande Walle J and Frémeaux.Bacchi V	Manifestations of atypical haemolytic uraemic syndrome (aHUS) in children and adults: data from the global aHUS registry	Global

# aHUS Registry : Congress ABSTRACTS

Year	Congress	Author	Title/Topic	Region
2015	SIN	Cresseri D, Licht C, Ariceta G, Cole A, gasteyger C, Cohen DJ, Greenbaum LA, Johnson S, Schaefer F, Vande Walle J, Frémeaux-Bacchi V and Ardissino	Caratteristiche di 406 pazienti in età adulta e pediatrica iscritti nel "Global aHUS Registry", registro internazionale per pazienti affetti da sindrome emolitico uremica atipica (SEUa)	Italy
2015	ISTH	Licht C, Ardissino G, Ariceta G, Cohen DJ, Gasteyger C, Greenbaum LA, Johnson S, Ogawa M, Kupelian V, Schaefer F, Vande Walle J and Frémeaux-Bacchi V	Baseline Demographics and Characteristics of 570 Patients with Atypical Hemolytic Uremic Syndrome in the Global aHUS Registry	Global
2015	ASN	Licht C, Ardissino,G, Ariceta G, Cohen DJ, Gasteyger C, Greenbaum LA, Johnson S, Ogawa M, Kupelian V, Schaefer F, Vande Walle J and Frémeaux-Bacchi V	Characteristics of 681 Patients with Atypical Hemolytic Uremic Syndrome in the Global aHUS Registry	Global
2015	ASH	Licht C, Ardissino,G, Ariceta G, Cohen DJ, Gasteyger C, Greenbaum LA, Ogawa M, Kupelian V, Schaefer F, Vande Walle J and Frémeaux-Bacchi V	The Global aHUS Registry: Characteristics of 826 Patients with Atypical Hemolytic Uremic Syndromet	Global
2014	GPN	Schaefer F, Frémeaux-bacchi V, Ariceta G, Ogawa M, Vande Walle J and Licht C	An observational, non-interventional, multinational registry of patients with atypical haemolytic uraemic syndrome: Initial patient characteristics	Germany
2014	BRS	Johnson S, Licht C, Ardissino G, Ariceta G, Beauchamp J, Greenbaum LA, Ogawa M, Schaefer F, Vande Walle J and Frémeaux-Bacchi V	Initial patient characteristics from the observational, non-interventional, multinational registry of patients with aHUS	UK
2014	EHA	Ariceta G, Vande Walle J, Johnson S, Ardissino G, Cohen DJ, Greenbaum LA, Ogawa M, Schaefer F and Licht C	Improving our understanding of atypical hemolytic uremic syndrome (aHUS): initial patient characteristics from an international registry	Global
2014	ERA-EDTA	Vande Walle J, Johnson S, Frémeaux-Bacchi V, Ardissino G, Ariceta G, Beauchamp J, Cohen DJ, Greenbaum LA, Ogawa M, Schaefer F and Licht C	Increased understanding of atypical haemolytic uraemic syndrome (aHUS): characteristics of patients recruited into the global aHUS registry	Global

# aHUS Registry : Congress ABSTRACTS

Year	Congress	Author	Title/Topic	Region
2014	ESPN	Licht C, Frémeaux-Bacchi V, Johnson S, Ardissino G, Vande Walle J, Cohen DJ, Greenbaum LA, Ogawa M, Schaefer F and Ariceta G	Increasing knowledge of atypical haemolytic uraemic syndrome through a global registry: characteristics of recruited patients	Global
2014	SINP	CresseriD, Johnson S, Frémeaux-Bacchi V, Ariceta G, Vande Walle J, Cohen DJ, Greenbaum LA, Ogawa M, Schaefer F, Licht C and Ardissino G	Approfondimento della conoscenza della sindrome emolitico uremica atipica (SEUa): caratteristiche dei pazienti arruolati nello studio di registro SEUa globale	Italy
2014	SEN	Ariceta G, Frémeaux-bacchi V, Ogawa M and Greenbaum LA	Profundizando en el conocimiento de la síndrome hemolítico atípico (SHUa): características de los pacientes reclutados en el registro mundial de SHUa	Spain
2014	SIN	CresseriD, Johnson S, Frémeaux-Bacchi V, Ariceta G, Vande Walle J, Greenbaum LA, Ogawa M, Schaefer F, Licht C and Ardissino G	Increased understanding of atypical haemolytic uraemic syndrome (aHUS): characteristics of patients recruited into the global aHUS registry	Italy
2014	SFNDDT	Frémeaux-Bacchi V, Ariceta G, Ardissino G, Johnson S, Ogawa M and Greenbaum LA	Amélioration de la compréhension du syndrome hémolytique urémique atypique par le biais d'un registre global : caractéristiques des patients inclus	France
2014	ASN	Licht C, Ardissino G, Ariceta G, Cole A, Gasteyger C, Cohen DJ, Greenbaum LA, Johnson S, Ogawa M, Schaefer F, Vande Walle J and Frémeaux-Bacchi V	Characteristics of 406 Adult and Pediatric Patients in the Global aHUS Registry	Global
2014	ASH	Licht C, Ardissino G, Ariceta G, Cohen DJ, Gasteyger C, Greenbaum LA, Ogawa M, Schaefer F, Vande Walle J and Frémeaux-Bacchi V	Baseline Demographics and Characteristics of 466 Patients with Atypical Hemolytic Uremic Syndrome in the Global aHUS Registry	Global
2013	ASN	Licht C, Ardissino G, Ariceta G, Beauchamp J, Cohen DJ, Greenbaum LA, Johnson S, Ogawa M, Schaefer F, Vande Walle J and Frémeaux-Bacchi V	An observational, non-interventional, multicenter, multinational registry of patients (pts) with atypical hemolytic uremic syndrome (aHUS): initial pt characteristics	Global
2013	ASH	Licht C, Ardissino G, Ariceta G, Beauchamp J, Cohen DJ, Greenbaum LA, Johnson S, Ogawa M, Schaefer F, Vande Walle J and Frémeaux-Bacchi V	Baseline demographics and characteristics of 119 patients with atypical Hemolytic Uremic Syndrome (aHUS) in the global aHUS Registry	Global

# Congress ACRONYMS

ACRONYM	
ASH	American Society of Hematology
ASN	American Society of Nephrology
ASPN	American Society of Pediatric Neurosurgeons
BRS	British Renal Society
EHA	European Hematology Association
ERA-EDTA	European Renal Association – European Dialysis and Transplant Association
ESPN	European Society of Paediatric Nephrology
GDfN	Deutschen Gesellschaft für Nephrologie
GPN	Gesellschaft für Pädiatrische Nephrologie
HAA	Haematology Society of Australia and New Zealand, Australian & New Zealand Society of Blood Transfusion and the Australasian Society of Thrombosis and Haemostasis
IPNA	International Pediatric Nephrology Association
ISTH	International Society on Thrombosis and Haemostasis
PAS	Pediatric Academic Societies
SEN	Sociedad Española de Nefrología
SFNDT	Société Francophone de Néphrologie, Dialyse et Transplantation
SIN	Società Italiana di Nefrologia
SINP	Società Italiana di Nefrologia Pediatrica

GL/SOL-aHUS/15/0008a  
US/SOL-aHUS/15/0016a